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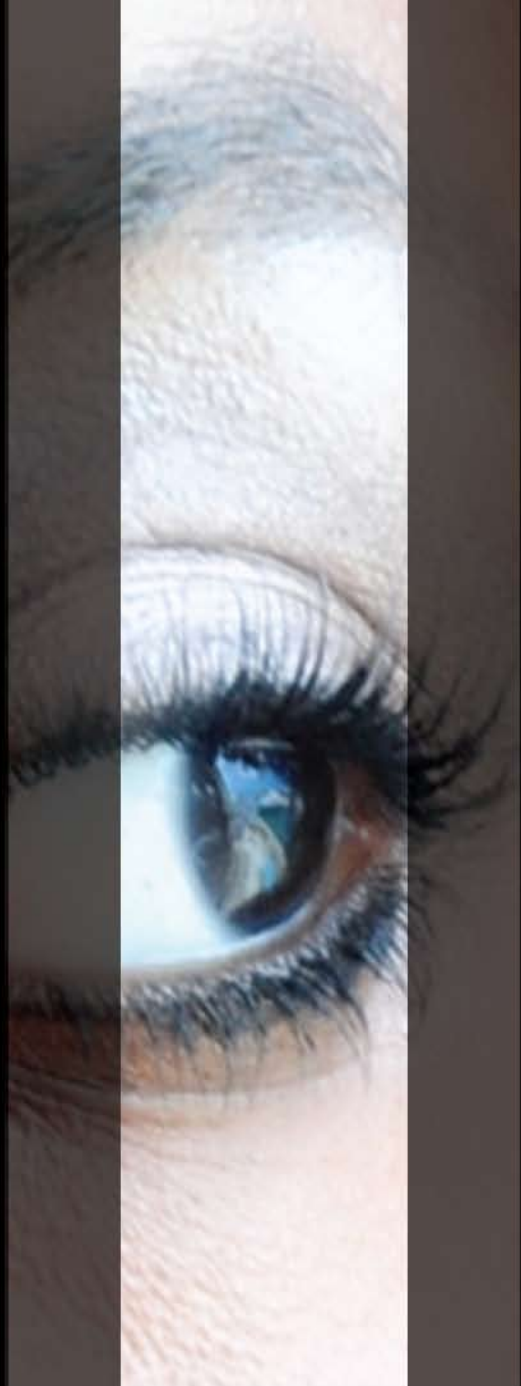
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Dr George Palattiyil
Dr Dina Sidhva



they call me
YOU ARE AIDS...



A Report on HIV, Human Rights
and Asylum Seekers in Scotland



they call me
YOU ARE AIDS...

A Report on HIV, Human Rights
and Asylum Seekers in Scotland

George Palattiyil and Dina Sidhva ©2011
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**BRITISH
ACADEMY**

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Executive Summary

Introduction

Migration can often have serious health consequences for migrants, as they may be vulnerable to discrimination and may experience language and cultural barriers and other economic and social difficulties due to their unique legal status. Since the emergence of the HIV (Human Immunodeficiency Virus) epidemic, migrant populations have received considerable recognition from the international community in the context of risk, transmission, and prevention of HIV and AIDS (Acquired Immune Deficiency Syndrome). Asylum seekers are an integral constituent of this international migrant population who may be at risk of HIV.

A considerable number of asylum seekers have come to the United Kingdom during past few years, although successive policies of the government in power have attempted to cut the overall number. The Joint Committee on Human Rights (2007) states that asylum applications within the UK increased from 32,505 in 1997 to 84,130 in 2002. Aspinall and Watters (2010) report that in 2008, there were 25,930 applications for asylum with 19,400 initial decisions made (11% fewer than in 2007). Those seeking asylum are often fleeing from countries that experience higher rates of HIV, and many asylum seekers are HIV positive themselves.

Since the introduction of the dispersal policy in 2000 by the UK Home Office, many asylum seekers who were HIV positive have been relocated to Scotland. Despite a growing awareness of the need to understand issues that affect this marginalised and vulnerable group, both qualitative and quantitative data remain limited. The principal objectives of this study, therefore, were to develop a deeper understanding of the experiences, human rights issues, and dilemmas faced by HIV-positive asylum seekers in Scotland. The intention of the study was to provide an in-depth understanding of lived realities of HIV positive

asylum seekers, in order to provide visibility and place more emphasis on their human rights in discussions of the way services are delivered to them.

Background

Migration and HIV/AIDS remain two of the largest social issues within the globalised world today, and HIV-positive AS experience a 'double jeopardy' as they are marginalised from resources as well as denied a number of basic human rights (Davies, 2006). The question of how the needs of HIV-positive AS fit within the context of international human rights and domestic policy demands greater attention.

In the UK, the immigration and asylum policies of the successive governments have created conditions that make management of HIV particularly difficult. Research indicates the ability for asylum seekers to physically manage HIV post-diagnosis is particularly challenging, because they experience a wide range of practical problems in comparison to non-AS (Weatherburn et al., 2003, as cited in Cherfas, 2006). Examples include the inability to eat appropriate foods due to inadequate financial support, the inability to prepare meals and conceal medication due to overcrowded housing and the anxiety created by uncertainty over whether treatment will continue due to fears of deportation.

Current Statistics

As of March 2011, there were just over 2,450 asylum seekers living in five different local authorities in Scotland. The following statistics provide a summary of the numbers of asylum seekers in Scotland, as of March 2011 (COSLA, 2011):

- There are currently 1,163 main applicants (amounting to 2,425 people) who are in receipt of full support.
- There are 18 applicants (amounting to 39 people) who are not accommodated by the United Kingdom Border Agency (UKBA) and who only receive subsistence support.
- A total of 301 main applicants (amounting to 443 people) in Scotland are in



receipt of Section 4 Support.

- Almost 60% of all AS in Scotland are nationals of just five countries: Peoples Republic of China (30%), Pakistan (11%), Iran (7%), Nigeria (6%) and Iraq (5%).

Health Care and Other Challenges for HIV-Positive Asylum Seekers

A complex combination of cultural, social, legal, institutional and structural barriers prevent asylum seekers and refugees living with HIV from successfully accessing adequate healthcare (Cherfas, 2006). Legal obstructions (such as denial of legal status, dispersal policies, lack of consistency regarding rights to healthcare), language barriers, stigma, marginalisation, social exclusion, religious beliefs, fear of discrimination, cultural attitudes, inconsistencies in services delivery and lack of information regarding the number of AS population affected by HIV act as deterrents and thus contributes to HIV vulnerability (Attawell, 2009). Having to seek asylum places AS and refugees in a position of vulnerability in itself, and health, particularly preventative care, is often not a priority (Cherfas, 2006). Additionally, tackling negative social attitudes, which are often enhanced by negative media attention, remains a key challenge (Attawell, 2009). Negative perceptions of rising numbers and costs associated with those seeking asylum has led to asylum seekers and refugees experiencing high levels of verbal and physical abuse, yet the reality is the number of people claiming asylum has reduced considerably (Aspinall and Watters, 2010). Cherfas (2006) suggests that if the health needs of asylum seekers are to be met, practitioners must focus on both past and current experiences that could be contributing to psychological distress, including the lack of control, instability and positions of powerlessness enforced upon them within the UK.

Methodology

Data was collected from HIV-positive Black African asylum seekers in a series of individual interviews and two focus groups. The interview participants included 19 participants (15 women and 4 men). Five of them were classified as

refugees, having been granted refugee status just prior to the interviews. The participants came from Zimbabwe Ivory Coast, Burundi, Ethiopia, Malawi, South Africa, Nigeria, Tanzania and Kenya. All participants lived in Glasgow and received support from Waverley Care's African Health Project. Two focus groups were held, one including 13 participants and one including seven participants. Most of the participants participated in an interview and a focus group; however, there were a few participants who participated in only one of the two activities.

The in-depth interviews used an open-ended format that encouraged participants to speak their own minds and to provide as much detail as they wished to include. The focus groups provided a forum for sharing experiences and mutual support and encouragement. All interviews and the focus groups were digitally recorded and transcribed.

Transcripts from the interviews and focus groups were analyzed for unique and recurring content. The content was organized into a series of themes that captured the experience of the participants.

Findings

Through the individual and focus group sessions, respondents were encouraged to share their thoughts and feelings in four topic areas: why they came to the UK, the experience of seeking asylum in the UK, their experience of being an HIV positive asylum seeker in the UK, and their hopes for the future. The findings for each of the four areas are summarized below.

Reasons for Coming

Fleeing violent situations, being in search of treatment, being a victim of human trafficking and overstaying on a student visa were cited as the four reasons why respondents left their countries of origin and came to the UK.

The Experience of Seeking Asylum

Three key areas emerged in relation to the asylum-seeking process:



bewilderment and uncertainty about the present and future, issues in relation to the United Kingdom Borders Agency (UKBA), and dispersal and detention.

Experience of Being an HIV-Positive Asylum Seeker

Among the themes that recurred for this topic were fear of disclosure, being under UKBA surveillance, being a failed AS and the unfathomable asylum system. Access to medical care was also discussed in much depth and with much animation during the focus group, along with the problems respondents faced with the voucher system. Other themes included the pain and shame experienced, experiences of stigma and labelling, the emptiness and the interminableness of their present existence, multiple jeopardy and finally the solace gained from support networks.

Hopes for the Future

When asked about hopes for the future, the participants spoke about their aspirations for freedom, medical care, being united with their families, and having the right to live and work freely and be productive members of society. They also said that one of their hopes for their future was that their voices would be heard from this study.

Conclusion and Recommendations

The study has uncovered conditions and treatment that present a real threat to the human rights and health of HIV-positive asylum seekers. There is a clear need for policy change, as well as improved education and training in sensitivity for government officials and others who work with this population. The following steps are recommended:

- There should be a rethink of how asylum seekers' applications are processed. Applications should be processed promptly and with sensitivity, so that these individuals are not forced to move from vulnerability to vulnerability; but from vulnerability to protection.
- It is imperative that asylum applications are processed in the light of the Convention Relating to the Status of Refugees, and not evaluated against a backdrop of political imperatives or media pressure. The immigration and

asylum process should be redesigned so that it does not create fear and anxiety among vulnerable individuals

- There is a need to revisit work-related rights and to give AS permission to work if they have been waiting for more than six months for their cases to be concluded, or if they have been refused asylum but cannot be returned home through no fault of their own. This will prevent vulnerable people being left in a state of limbo for prolonged periods of time, will reduce the burden on the taxpayer, and will allow a small number of asylum seekers to support themselves and their families while contributing to the economy.
- There is a clear need for culturally sensitive awareness training, targeting specifically at influencing attitudes and approaches of health care providers and health service staff towards HIV-positive AS. Such a programme should also include developing more culturally competent services, tailor-made to the needs of HIV positive people.
- There is a need for the UKBA to develop a clearer understanding of the availability and accessibility of appropriate care and treatment for HIV in the country of origin of the AS, before deporting AS. Deportation can not only deny AS the right to health; it can also worsen health conditions, potentially leading to the death of AS. While claimants' narratives need to be deemed credible and consistent, they need to be cross-checked more thoroughly with information about the country of origin.
- There is a need to renew our commitment to human rights as a cornerstone for informing policy and practice in relation to HIV-positive AS. Government authorities should end human rights violations such as the policy of destitution that affects the health of individuals. The authorities should provide leave to remain, permit AS to work, and allow for access to food and other necessities of treatment.
- Right to family life is enshrined in the Human Right Act, and respect for human rights is essential for effective responses to HIV/AIDS, as infringements of human rights lie at the heart of marginalisation and the creation and continuation of vulnerability (UNAIDS, 2001). Furthermore, dispersal is seldom planned in advance, and no consideration is given to the health/medical needs of an HIV-positive AS. There is a clear need to rethink ways in which dispersal can be improved, such that the negative effects of dispersal on HIV-positive AS can be eliminated.



- There is a clear need to engage counselling and psychological services from early on to deal with the trauma and stress experienced by HIV-positive AS. Assessment and treatment for PTSD should be carried out as a matter of course, and AS should be provided with advocacy services that will empower them to tell their stories.
- Health consultants who provide treatment to HIV-positive AS should campaign and advocate for these vulnerable individuals with their local politicians and raise the profile at the central government level by lodging complaints and supporting campaigns to help AS, such that their voices will inform policy decisions.
- It is evident that the work done by the voluntary organisations in supporting the HIV positive AS was exemplary; however many of these activities rely on very tight and ever shrinking budgets. The sustainability of these organisations is dependent on guaranteed funding, and there is a need for clear commitment from the government to continue this funding for enabling AS to integrate better into the wider community.
- It is vital that special advocates are appointed for each asylum applicant at the time of first application, so that each AS will have a person who can guide them through the entire process, who can also speak the native language, and who will have sufficient sensitivity to understand their needs and their limitations.
- The most appropriate solution for an AS without high support needs, would be to put them in touch with a legal service to ensure that there is no further legal recourse for them in terms of their asylum claim and, if there is no recourse, to initiate voluntary repatriation or deportation.
- An ongoing legal action prevents the Government from removing refused asylum seekers to Zimbabwe. Steps should thus be taken to provide a safe haven for destitute Zimbabweans (Amnesty International, 2011).

"Every time the doorbell rings I freeze...I think they have come to deport me; every time I see the police, I am paralysed...I am terrified they are looking for me; you know that's my life... my heart's in my mouth, and how can I find the strength to fight the virus?" (Anonymous, Sudanese Asylum Seeker)



Chapter 1: Introduction

1.1 Background:

Internationally, migration has been a growing concern for policy makers and governments, as it impacts on several areas of national policy. Global migration, as defined by the World Health Organization (WHO, 2003) is the movement of people from one area to another for varying periods of time, arising out of economic and environmental factors, war, and political influences (Attawell, 2009). Global migration is vast and continues to grow (Human Rights Watch, 2009). International migration is estimated to have more than doubled in the last 40 years, from 76 million in 1965 to 191 million by 2005 (Attawell, 2009; Taylor, 2006).

Migration can often have serious health consequences for migrants, as they may be vulnerable to discrimination and may experience language and cultural barriers and other economic and social difficulties due to their unique legal status. Since the emergence of the HIV epidemic, migrant populations have received considerable recognition from the international community in the context of risk, transmission, and prevention of HIV/AIDS. Asylum seekers are an integral constituent of this international migrant population who may be at risk of HIV.

A considerable number of asylum seekers have come to the United Kingdom during past few years, although successive policies of the government in power have attempted to cut the overall number. For example, the UK received 262,400 asylum seekers during the period from 2002 to 2006 (UNHCR, 2007). The Joint Committee on Human Rights (2007) states that asylum applications within the UK increased from 32,505 in 1997 to 84,130 in 2002. Aspinall and Watters (2010) highlight that in 2008, there were 25,930 applications for asylum with 19,400 initial decisions made (11% fewer than in 2007). Those seeking asylum are often fleeing from countries that experience higher rates of HIV, and many

asylum seekers are HIV positive themselves.

The increase in asylum applications and the demand for services led to a rethink by the Home Office of how best asylum seekers can be managed. One of the consequent developments from this is the dispersal policy of the UK government where asylum seekers are dispersed to different parts of the UK. Since the introduction of the dispersal policy in 2000 by the UK Home Office, many asylum seekers who were HIV positive were relocated to Scotland. Current research on the impact of HIV-positive asylum seekers in Scotland is sparse. Tallis (2002:18) argues that programmes designed to tackle HIV/AIDS must include the “lived realities” of those affected and ensure they are involved in both defining the problem and reaching a resolution. Yet there remains a significant absence of AS experiences documented by research (Bowes et al., 2009). Despite a growing awareness of the need to understand issues that affect this marginalised and vulnerable group, both qualitative and quantitative data remain limited.

The HIV/AIDS pandemic is a global concern that has left an indelible mark on the health and social fabric of almost every country in the world. A recent report estimates that 33 million individuals are living with HIV (UNAIDS, 2010). The incidence of HIV in the UK continues to rise, with over 86,500 people living with HIV in 2009 (Health Protection Agency, 2010). In 2010, there were 6,136 new diagnoses of HIV, and as of December 2010, there have been 26,791 diagnoses of AIDS (Avert, 2010), with the diagnosis rate for Black Africans being three times higher than that of the general population (National AIDS Trust, 2008).

According to the Health Protection Agency Scotland (2011), there has been a rise in the annual number of reported cases of HIV in Scotland. In 2011, 258 new cases were reported. The Health Protection Agency estimates that there are currently 4059 persons living with HIV in Scotland, of whom 3339 are attending for specialist care and treatment. This includes a number of asylum seekers with uncertain immigration status, who since the introduction of the dispersal policy in 2000, have been moved to Scotland.



The very issues that compel people to seek asylum are the ones that drive the AIDS epidemic and make asylum seekers particularly vulnerable to HIV (Haour-Knipe, 2003). HIV thrives in regions of poverty, conflict, and inadequate living conditions (Spiegel and Nankoe, 2004; Davies, 2006). The lives of asylum seekers are very much characterised by these issues; therefore, they can be more susceptible to the disease, as they are often placed in positions of powerlessness. HIV-positive asylum seekers experience poverty, isolation, vulnerability, stigma, and discrimination, which when coupled with a lack of support and access to appropriate medical care, have the potential of denying fundamental human rights and dehumanising people who are already fleeing circumstances threatening their very existence.

1.2 Purpose of the study:

Many asylum seekers who are dispersed experience serious consequences to their health and wellbeing. Although asylum seekers are an increasingly visible group within Scottish society, little is known about the ways their health needs are being met and the vulnerabilities they experience on account of being HIV-positive and living with the potential threat of deportation. The principal objectives of this study, therefore, were to develop a deeper understanding of the experiences, human rights issues, and dilemmas faced by HIV-positive asylum seekers in Scotland. The intention of the study was to provide an in-depth understanding of lived realities of HIV positive asylum seekers, in order to provide visibility and place more emphasis on their human rights in discussions of the way services are delivered to them. It is hoped that their voices inform policy by influencing attitudes, behaviour, and decisions, with the key outcome ensuring that no one living with HIV is deported to a country where access to treatment is unavailable or beyond the reach of these vulnerable people.

The narratives from the HIV-positive asylum seekers who took part in this study provide a chilling glimpse of their lived experiences as they have journeyed from their own countries to a country they call 'home' today. On the one hand, these themes portray their vulnerabilities, struggle, and risks to personal safety juxtaposed against the backdrop of denial of support and potential deportation

by the UKBA to a country where HIV treatment is limited or beyond their reach. On the other hand, the narratives attest to the unstinting care and support asylum seekers receive from a few voluntary agencies and a specialist HIV clinic.

The emerging findings indicate a number of issues relevant for a critical debate about how the wellbeing and human rights of HIV-positive asylum seekers in Scotland are being affected by current policy. Critical also to this debate are the issues of stigma on disclosure of HIV within one's own community and outside, and the UKBA's 'culturally insensitive' and at times 'inhumane' practices.

1.3 Policy Context:

Human rights of HIV positive asylum seekers has received increased policy attention in the past few years, because the human rights of HIV-positive persons transcend nations and borders, and the realisation of their rights and fundamental freedoms is vital in reducing vulnerability to HIV/AIDS. There is an increasing commitment for human rights to take centre stage in the care and prevention of HIV globally. This was emphasized with the "Declaration of the Human Rights and HIV/AIDS: Now More than Ever" at the 2008 International AIDS Conference in Mexico City.

The insights gained from this study will be useful in informing services and policies in improving services in Scotland. It is hoped that listening to HIV-positive asylum seekers and disseminating their voices will illumine human rights issues that are essential in catalysing action in the global struggle against HIV/AIDS.

This report contains a literature review that examines the context of globalisation, migration and asylum seeking; policies and legislations that have particular relevance for asylum seekers, and human rights laws and practice in relation to HIV-positive asylum seekers. The methodology chapter then provides a glimpse of the methodology used in carrying out research in a particularly sensitive area. Later chapters include findings, a conclusion, and recommendations.



Chapter 2: Literature Review

HIV-Positive Asylum Seekers and Refugees in Scotland

2.1 Introduction

Current research on HIV-positive asylum seekers (AS) and refugees in Scotland is sparse. Since the dispersal policy was introduced in 2000, there has been a growing awareness of the need to understand issues that affect this marginalised and vulnerable group. Nevertheless, both qualitative and quantitative data remain limited. The purpose of this literature review is to gather information to examine the experiences, human rights issues and dilemmas faced by HIV-positive AS in Scotland. Drawing on research material from a variety of sources, this literature review will explore the impact of globalisation and migration, legal frameworks at international and national levels and the experiences of living with HIV in a new country. Consideration will be given to the multiple forms of discrimination this group experiences in getting their needs met.

2.2 Globalisation and migration

The term 'globalisation' remains contested; however, it broadly relates to the processes of increased international integration (Cousins, 2007). A direct result of globalisation is the increased number of people travelling to and from different countries. International migration is estimated to have more than doubled in the last 40 years, from 76 million in 1965 to 191 million by 2005 (Attawell, 2009; Taylor, 2006). Levels of migration are affected by economic and environmental factors, war and political influences (Attawell, 2009). The creation of the EU has arguably restricted some global pressures, as it has established standards of social provision/protection and expanded citizen rights. The creation of the United Nations Convention Relating to the Status of Refugees (UNHCR) and the United Nations Convention on Human Rights (UNCHR) have also had an impact. On the other hand, policy responses for

dealing with increased migration vary cross-nationally and have increasingly become more restrictive and punitive across Europe (Norredam et al., 2005; Phillimore, 2011). For example, Norredam et al. (2005) highlight that rather than grant asylum seekers medical rights afforded to the citizens of host countries, nearly half of the countries within the EU confine asylum seekers to accessing health care in emergency situations only.

Webber (2011) argues, “At the heart of globalisation is ruthless social Darwinism, which is reflected in and reinforced by immigration controls”. He goes on to draw attention to the extent of global injustice and highlights the fact that AS tend to be from poor countries that operate to serve the interest of rich countries. Consequently, the lives of AS are often shaped by discriminatory policies of powerful nations. Not granting AS the same rights and obligations as nationals within the country they are living is in direct contradiction to the UNHCR principles of equal treatment and non-discrimination. A recent report by UNHCR (2011:5) notes a decline in the importance of Europe as a destination for AS, which may reflect the policies described here. Between 2005 and 2009, the percentage of asylum applications for the 38 countries in Europe declined from nearly 60 per cent to around 45 per cent.

Since the 1990s, concern has risen over rising numbers of AS and undocumented migrants entering the UK (Phillimore, 2011). This concern has led to greater emphasis on control, surveillance and deterrence. Lewis (2003:324), as cited in Phillimore 2011, argues that migrants have become “the most demonised groups of people living in the western world”. Conversely, the government and the media have set out to place AS within the context of broader migration, yet they are not afforded the same rights (Aspinall and Watters, 2010). Feller (2006) argues that this process is used to encourage xenophobia and allows both the media and politicians to misrepresent this vulnerable group. Feller (2006) makes a clear distinction between ‘refugees’ and ‘migrants’ and emphasises that AS often have few legal choices and regularly have to find alternative means when fleeing their country of origin. Refugees have different rights from migrants and are afforded international protection under EU and human rights frameworks.



Migration and HIV/AIDS remain two of the largest social issues within the globalised world today, and HIV-positive AS experience a 'double jeopardy' as they are marginalised from resources as well as denied a number of basic human rights (Davies, 2006). The question of how the needs of HIV-positive AS fit within the context of international human rights and domestic policy demands greater attention.

2.3 UNHCR and EU Framework / Human Rights Legislation

In policy the definition of migrants and AS are often not distinguished, yet key differences remain. A migrant is defined by the United Nations as being "any person who lives temporarily or permanently in a country where he or she was not born, and has acquired some significant social ties to the country" (IOM, 2008). Thus, there can be an element of choice in migrating to another country. In contrast, AS often flee their native countries in fear of their lives. It is estimated the UNHCR have directives for nearly 10 million refugees (UNHCR, 2003). The majority of these people stay close to their country of origin; however some travel to countries within the EU to seek asylum (Norredam et al., 2005). Unlike migrants, AS are entitled to seek and enjoy asylum and are granted legal protection under international guidelines. Feller (2006:516) highlights,

Refugees lack the protection of their own governments and benefit from an internationally endorsed protection framework, supplemented by constitutional, legislative and 'soft law' guidelines to ensure their proper treatment. Refugees can also benefit from the services of a UN agency, UNHCR, which was specifically created to ensure their protection and assistance. In this sense, refugees have a distinct legal personality and a particular internationally recognised regime to address their needs.

Article 14 of the Universal Declaration of Human Rights grants a person the right to seek asylum, stating, "Everyone has the right to seek and to enjoy in other countries asylum from persecution" (United Nations, 2007; Feller, 2006).

Additionally, under the 1951 UNHCR, asylum can be granted to a person if they have a “well founded fear of persecution on the grounds of race, religion, nationality, membership of a particular social group or political opinion”.

The Dublin Convention on the rights of asylum was signed by all member states in 1990. A primary objective was to ensure that applicants could not apply for asylum in a number of member states at the same time (Hantrais, 2007). It established the idea of a “safe third country” and gave EU countries the right to remove applicants who had travelled via another “safe” EU country back to that place (Health Protection Agency, 2006).

The recent expansion of the EU has impacted migration, which in turn affects health provisions for this section of the population (including the treatment of HIV). Increased globalisation and migration has raised awareness of the vast numbers of people affected by HIV and the extent of marginalisation/stigma they experience. Thus, the EU and UNHCR have considered ways the disease can be prevented and alleviated. In 2004, The Dublin Declaration on Partnership to Fight HIV/AIDS in Europe and Central Asia led to the introduction of the 2002-2004 Strategic Plan on HIV/AIDS and Refugees, which, based on a human rights framework, aims to ensure that refugees are able to “live in dignity, free from discrimination, with their human rights respected” (Spiegel and Nankoe, 2004:23; UNHCR, 2002).

At the Lisbon Conference in 2007, the issue of health and migration was once again placed on the European agenda and led to agreement that the European Centre for Disease Prevention and Control (ECDC) would review migrant access to HIV prevention, treatment and care (Attawell, 2009). Attawell (2009:1) argues that these policies emphasise the political commitment of the EU “to ensure migrants have access to healthcare, including HIV prevention, treatment and care services”. Nevertheless, it is recognised that there are major variations on delivery of policies among individual member states. It must also be noted that the systematic exclusion of AS from policies and development programmes within the UK are at direct odds with the UNHCR aims.



O'Mahoney and Sweeney (2010) note that although the UNHCR sets out the legal definition of 'refugee', the processes used to determine whether a person meets the criteria are discretionary. Individual member states attempt to balance national rights with individual rights. In the current socio-political climate, the right to national sovereignty is placed above the individual human rights of AS, particularly the following rights as contained within the Universal Declaration of Human Rights (United Nations, 2007):

Article 2 – the right to life

Article 3 – prohibiting torture and “inhuman or degrading treatment or punishment”

Article 5 – stating that everyone has the right to liberty and security of person

Article 6 – the right to a fair trial

Article 8 – the right to respect for one's “private and family life, his home and his correspondence”

Article 14 – prohibiting discrimination based on “sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status”

Legal decisions at a local level are associated with decisions at a national and international level. For example, there are various levels of legislation participation for countries belonging to the EU. Regulations are enforceable and effective immediately, yet directives present minimum standards, with discretion in translation to national policy. These directly impact on law, policy and practice. For instance, the Human Rights Acts 1998 (derived from the European Convention on Human Rights [ECHR]) grants legally enforceable rights. Article 12.1 of The International Covenant on Economic, Social and Cultural Rights (ICESCR) sets out the international human right to health and was ratified by the UK in 1976. This recognises that everyone has the right to attain the highest standard of physical and mental health, including access to medical services (Davies, 2006). The ICESCR have stated that member states should respect the universal right to health and promote equal access to all (Davies, 2006).

The Office of the United Nations High Commissioner for Human Rights (OHCHR), as cited by Davies (2006:13) has stated, “The protection and promotion of human rights are... essential in preventing the spread of HIV and to mitigating the social and economic impact of the pandemic” and “In an effective international response to the pandemic there must be grounded in respect for all civil, cultural, economic, political and social rights”. At a national level, the UK Government has committed itself to ensuring that policies adhere to the principles contained within the ECHR. Consequently international human rights policy instruments can be utilised to protect rights and promote anti-discrimination for people affected by HIV/AIDS (Davies, 2006). A human rights approach can be used to evidence the impact of governmental policies on AS, challenge social injustice and hold member states accountable for their human rights obligations (Donald and Mottershaw, 2009:27). Feller (2006:525) argues that the 1951 Convention “gives a voice and force to the rights of refugees”.

Nevertheless, difficulties arise in how member states use their legal powers to interpret human rights, as many of the underpinning principles are not legally binding. The 1951 Convention may determine the rights of AS, but it does not explain what responsibilities member states have for ensuring that these are enacted. Feller (2006:525) states that with regard to rights, the Convention “is close to silent about whose responsibility it actually is to protect them in the context of modern displacement situations and population movements.” For instance, in 2005 the House of Lords ruled that failed AS with HIV/AIDS do not have the right to stay in the UK to receive treatment and that deportation would not constitute a breach of Article 3 of the ECHR (Davies, 2006). Thus, despite international human right laws being in place, narrow interpretation can result in many people being denied these rights. Accordingly, many AS continue to be directly discriminated against, particularly HIV-positive AS (Davies, 2006). Ironically, the 2005 ruling was judged on the premise that the person was not at a ‘terminal stage’ of illness; however, the person’s state of health was due to the HIV treatment accessed within the UK (Bettinson and Jones, 2007).



Section 6 of the Human Rights Act 1998 specifies that courts must act in accordance with the ECHR. Bettinson and Jones (2007) point out that due to the level of stigma associated with HIV/AIDS in some countries, in certain circumstances returning AS to their country of origin could contravene Article 3 of the ECHR and constitute persecution under Article 1A (2) of the 1951 Refugee Convention. This evidences the subjective interpretation of human rights being applied. The Joint Committee on Human Rights (2007a, as cited in Aspinall and Watters, 2010:8) state: "Asylum seekers, regardless of their immigration status, are human beings, with fundamental and basic rights, needs and aspirations ... the UK's treatment of asylum seekers says something about the society we live in and the kind of country we want to be". Davies (2006) argues that the UK is failing in its duty to apply the international right to health enshrined in the ICESCR. Both the ECHR and the 1966 International Covenant on Civil and Political Rights prohibit 'unjustified' discrimination on the grounds of nationality (Joint Committee on Human Rights, 2007). Nevertheless, as previously discussed, what is determined to be unjustified is open to interpretation.

Malloch and Stanley (2005) draw attention to the ways that AS are represented within the media and political discourse and argue that this perception is used to justify increased use of incarceration. AS are regularly depicted as being dangerous, scroungers, criminals and 'undeserving' and therefore "effectively lose their eligibility for human rights protection, social resources and aid" (Malloch and Stanley: 2005:55). This raises social and ethical concerns. Supporting AS to access their rights demands "a comprehensive international response founded on solidarity, burden and responsibility- sharing and agreed rules and principles" (Feller, 2006:519). Nonetheless, there has been a paradigm shift from viewing an AS as a "victim fleeing persecution and entitled to sanctuary" to an "illegal immigrant, a potential terrorist, a transnational criminal or at best a likely abuser of the national asylum system" (Feller, 2006:536).

2.4 Legal Framework within the UK

Immigration policy has changed over the last two decades and has become increasingly harsh for AS and refugees. There is a wide body of literature to evidence the rapid pace of amendments to immigration policy within the UK, all of which appear to be aimed at prevention and deterrence (Aspinall and Watters, 2010; Crawley et al., 2011; Davies, 2006; Joint Committee on Human Rights, 2007; Stewart and Mulvey, 2011). The Immigration and Asylum Appeals Act 1993 incorporated 1951 UNHCR into UK law and established the right to appeal decisions for refused AS (within strict timescales); it also restricted housing rights. For example, it states that AS are ineligible for housing assistance if any viable alternative exists and where there is eligibility it should be “regarded as temporary only” (O’Mahony and Sweeney, 2010:303). The Asylum and Immigration Act 1996 made it a criminal offence to employ AS unless they have permission to live and work in the UK. It also removed homeless accommodation rights for all people subject to immigration controls (Humphries, 2004).

Crawley et al. (2011) set out six major pieces of legislation enacted from 1997 to 2010 and noted that support given is dependent on immigration status. AS whose applications are refused or are being appealed are particularly vulnerable. The 1996 Asylum and Immigration Act withdrew rights to welfare for those who did not claim upon arrival; however, the 1999 Asylum and Immigration Act has been cited as being one of the most radical and controversial pieces of legislation, as it introduced the National Asylum Support Service (NASS) for supporting/dispersing destitute asylum seekers, removed benefit entitlements from AS applicants and limited additional payments for families (Crawley et al., 2011). This Act made a distinction between support given to AS and refugees and support granted to citizens. For example, it removed rights of AS to claim state benefits and set support for AS below the poverty line at 70% of income support (Humphries, 2004). It also removed the right to temporary housing from local authorities and replaced it with Section 95, which allows NASS



discretion to support AS if they are (or likely to become) destitute (O'Mahony and Sweeney, 2010). The Act also introduced what has come to be known as Section 4 payment, where NASS can provide minimal support to destitute failed AS. However, Section 4 support relies on failed AS complying with certain conditions detailed under the Immigration and Asylum (Provision of Accommodation to Failed Asylum Seekers) Regulations 2005 including regular reviews reporting conditions and arrangements to facilitate departure (Joint Committee on Human Rights, 2007). The Nationality, Asylum and Immigration Act 2002 placed emphasis on controlling/removing unsuccessful applicants. The right of AS to work after six months was removed (Bowes et al., 2009). Additionally, Section 55 allows AS to be denied accommodation if it is deemed that they did not apply for asylum "as soon as reasonably practical" (O'Mahony and Sweeney, 2010:302).

Fortier (2003) points out that Section 55 has left many AS completely destitute, as some have been denied any form of support despite applying within days of arrival. Crawley et al. (2011) note that in 2003, 9,000 AS were denied support under S55 and the Court of Appeal subsequently found the Home Office to be in breach of Article 3 of the ECHR. The Asylum and Immigration Act 2004 introduced substantive changes to the asylum appeal process and asylum support and created penalties for arriving in the UK without documentation. For instance, it included a clause to remove access to basic support for AS at the end of the appeal process. Additionally, Section 95 allows children with families to receive financial support and accommodation, but Section 9 grants government the power to stop ALL support. These laws can therefore prevent local authorities from helping if it is thought that families or individuals are not taking "reasonable steps" to leave the country (Crawley et al., 2011). They can also attach a condition of "community activity" to hard case support (Stewart, 2005).

The National Health Service Regulations 2004 was another controversial piece of legislation. Kelly and Stevenson (2006:7) note that under this legislation, although AS are entitled to free NHS care, once refused and all appeal rights are exhausted, whilst "they remain entitled to continue any treatment they

were already receiving...all other secondary care is chargeable". This had led to undocumented migrants being prevented from accessing free treatment for HIV/AIDS (Davies, 2006). The Immigration, Asylum and Nationality Act 2006 created a five-point tier system for awarding visas and further limited rights to appeal. It created an employers civil penalties scheme aimed at tackling those working illegally and introduced information sharing between immigration, police and customs (Health Protection Agency, 2006).

Crawley et al. (2011) note that once AS applicants are refused and have exhausted all rights of appeal, they are told they cannot work and are expected to leave country within 21 days. For refused AS with no children, financial support and accommodation cease, although some may be able to access Section 4 support if they can prove they are destitute and taking steps to leave country (or if deemed by UKBA not safe to return). They are also only entitled to primary care and can be placed in detention centres by the UKBA (Crawley et al., 2011). Sales (2002:456) argues that UK immigration policy "has increasingly dichotomised two sets of arrivals, the deserving refugee and the undeserving asylum seeker".

Briskman and Cemlyn (2005:716) argue UK policy undermines human rights obligations and note the erosion to asylum rights and the limitations adherence to the 1951 UN Convention produced by recent legislation. Recent policy changes emphasise deterrence and punishment and have led to an increase in detention, surveillance and deportation (Briskman and Cemlyn (2005:715). A report by AVID in 2002 estimated that 25% of AS held in detention centres were awaiting an initial decision and 24% were awaiting appeal. The increased use of detention centres and restrictive policies contradicts international human rights obligations and results in AS being treated inhumanely (Briskman and Cemlyn, 2005). For example, Burnett et al. (2010) draw attention to the high numbers of suicide attempts and life threatening situations experienced by HIV-positive AS in detention centres. These are caused by routine failures within these institutions to provide adequate medical care. Moreover it highlights numerous instances of degrading treatment and breaches of confidentiality (Burnett et al., 2010). Consequently, the right of the UKBA to control and remove AS is placed



above the universal right stated in Article 3 of the UNHCR, that all individuals should be free from “inhuman or degrading treatment or punishment”.

NASS is responsible for dispersal and determining what level of support AS should receive. NASS support continues until a decision is made on the AS's application. Decisions include being granted refugee status, being granted permission to remain in the UK with certain conditions (without refugee status) for a limited period, or having claims rejected (thus subject to possible deportation; Bowes et al., 2009). Refugee status used to be granted for life; however, since 2005 it has been limited to five years, after which it is subject to review (Chantler, 2011).

Aspinall and Watters (2010) draw attention to the incongruity of Section 55 and 9 of immigration legislation with human rights legislation, particularly Articles 3 and 8 of the ECHR. They note that the narrow conditions AS must meet to in order to receive Section 4 support raise doubts over whether the UK is meeting its legislative responsibilities at both a national level and an international human rights level. International human rights policy instruments denounce the use of stigmatisation and discrimination in law. Nevertheless, they continue to be used in both UK policy and practice, especially in relation to HIV-positive AS (Davies, 2006). Ironically, continued denial of HIV treatment for some marginalised groups increases the risk of transmission to other sections of society (Fortier, 2003).

2.5 Human Rights, Asylum Seekers and HIV

Davies (2006) and the Joint Committee on Human Rights Report (2007) are good resources that set out universal rights entitlements, noting UK policies which potentially breach them. For example, the Joint Committee on Human Rights report (2007:17) notes that treatment resulting in destitution causing severe suffering or poor living conditions may breach Article 3 or, if the suffering is less severe, Article 8. If treatment or the absence of such treatment results in the death of an individual, it may breach Article 2 – the right to life. Articles 2, 3 and 8 are particularly relevant when considering access to healthcare for

AS (Joint Committee on Human Rights, 2007). Davies (2006) points out the universal right to health described in Article 12.1 of The International Covenant on Economic, Social and Cultural Rights (ICESCR; ratified by the UK in 1976) and notes its provision that policies should promote equal access to all.

Significant to this debates is the fact that a majority of AS seek support under S95 of the 1999 Act, while applications are being processed. This support is set below income support levels and until recently was granted in the form of vouchers (now a payment card) and no-choice dispersal accommodation. Additionally, since 2002 the right of AS to work has been removed. For destitute AS whose application has been refused or is being appealed, S95 support is removed. Section 4 support may be available, but it is dependent on certain conditions being met. Shisheva (2010) draws attention to the difficulties in maintaining family unity due to the no-subsistence-only option under Section 4 support. Additionally, appeals against decision made by the UKBA have to be actioned within strict timescales. For example, the Scottish Refugee Council (2010) notes that AS have ten working days (only five if they are being detained) to lodge any appeal. This has implications for people who are HIV-positive and undergoing treatment. Additionally, research by Smart (2009, as cited in Mulvey, 2009a), highlights that many destitute AS will simply refuse to apply for Section 4 so they will not be committed to returning to the country they have left.

The various policies in relation to asylum in the UK have impacted on AS in different ways, with significant human rights implications. Threats of dispersal and/or detention and restrictions to health care, combined with policies which enforce poverty and wider social inequalities, enhance health difficulties associated with HIV (Anderson, 2008; Aspinall and Watters, 2010).

The Azure card that was introduced in November 2009 replaced supermarket vouchers. However, this new card system continues to restrict where and when people are able to shop, what they are able to buy, and often not working at all. This system has failed to assuage any of the inherent problems of a cashless payment system which means already vulnerable individuals are faced with



turning to risky and illegal ways of obtaining cash to meet their basic needs and those of their families (Singh, 2010).

Further, in discussing the new Azure payment card, Reynolds (2010) draws attention to difficulties many face in managing their allowance. Over a quarter of interviewees reported not knowing how to use the telephone service and there is £5 carry over limit applied to single AS. This can cause distress, shame and hunger when individuals unknowingly use up their allowance. Additionally, the carry over limit is “disproportionately punitive and causes additional hardship” (Reynolds, 2010:5). Additionally, over 50% of interviewees reported being unable to travel to medical and legal appointments, nearly 50% are unable to travel to meet friends and family and 20% are unable to buy telephone cards (Reynolds, 2010). This potentially breaches human rights on numerous levels. For example, Article 6 – the right to a fair trial and Article 8 the right to family life. Moreover, Reynolds (2010:6) argues that it denies AS the freedom and ability to participate in community life and “potentially breaches the UKBA’s Section 55 duty to safeguard and promote the welfare of children”.

The research indicates a cashless system increases the stress and stigmatisation experienced by AS. For example, 56% reported feeling humiliated using the card, 38% reported experiencing discriminatory attitudes from retail staff and 33% reported experiencing hostile and negative attitudes from other consumers (Reynolds, 2010).

Accordingly, many AS will look at alternative methods to obtain cash, which increases the risk of them experiencing exploitation and danger in attempting to get their basic needs met (Reynolds, 2010). Additionally, the administrative and technical difficulties of a payment card system increase the likelihood of hardship and destitution. For instance, 79% of interviewees reported retail staff either refusing to accept the card or not knowing how it should work, over 60% stated there have been instances of the card not working and over a quarter reported delays in receiving entitlements (Reynolds, 2010).

Additionally, the policy of charging refused AS for HIV treatment and deporting them back to countries where there is insufficient access to medical treatment raises concerns on humanitarian grounds (Aspinall and Watters, 2010). “Not only is it inhumane to diagnose but not treat HIV/AIDS, it also undermines the Government's commitment to managing the spread and effects of HIV/AIDS worldwide” (Davies, 2006:4).

The quality of accommodation and services offered to AS is limited and in some cases appears to contradict Article 8 of the ECHR, respecting the family and home (Aspinall and Watters, 2010). Moreover, denying medical care based on immigration status runs counter to Article 14 of ECHR. Davies (2006:20) points out that denying AS affected by HIV the right to healthcare “is ethically indefensible, unlawful from a human rights perspective and extremely damaging to individual and public health”. Additionally, the separation of other STI's and HIV for the purpose of free treatment is discriminatory (Gazzard et al., 2005).

The recent report by the Joint Committee on Human Rights (2007:35) concludes that by refusing permission for AS to work and operating a system of support which results in widespread destitution, the Government's treatment of AS in a number of cases breaches the Article 3 ECHR threshold for “inhuman and degrading treatment”

Da Lomba (2010:431) argues the immigration process prevents integration of AS, as it is determined by “inferior legal status that lacks certainty”. Da Lomba argues that the differential treatment of AS could constitute a violation of Article 34 of the Refugee Convention (UNHCR 2009: para. 4; Refugee Council 2009b: 4), which requires participating states to facilitate naturalization of refugees (Da Lomba, 2010:432). Sales (2005, as cited in Da Lomba 2010:433) emphasises that current practice “feeds xenophobia and racism”.

The immigration and asylum policies of the successive governments have created conditions that make management of HIV particularly difficult. Research indicates the ability for asylum seekers to physically manage HIV



post-diagnosis is particularly challenging, because they experience a wide range of practical problems in comparison to non-AS (Weatherburn et al., 2003, as cited in Cherfas, 2006). Examples include the inability to eat appropriate foods due to inadequate financial support, the inability to prepare meals and conceal medication due to overcrowded housing and the anxiety created by uncertainty over whether treatment will continue due to fears of deportation. Additionally, having to share bathrooms and inadequate living conditions with a number of people, whilst experiencing difficult symptoms associated with HIV treatment can make living with the disease less manageable (Fortier, 2003). Crawley et al. (2011:6) argue, “overwhelming lack of access to institutional, social and economic resources denies AS a sustainable livelihood and results in a life that is robbed of dignity and unacceptable by human rights standards”.

2.6 Current Data on AS and Refugees in Scotland

As of March 2011, there were just over 2,450 asylum seekers living in five different local authorities in Scotland. Glasgow City Council is currently the only local authority in Scotland that accommodates dispersed asylum seekers. Outside of Glasgow City Council, there are 12 main applicants (amounting to 27 people) living with friends or relatives in four other local authorities. The most recent figures (2008) show that there are 2,208 asylum-seeking children and refugees attending schools in Glasgow. This is 3.3% of the total school population, of which 814 (1.2%) are AS, and 1,394 (2.1%) are refugees (Glasgow City Council Pupil Census Results, September 2008).

The following statistics provide a summary of the numbers of AS in Scotland, as of March 2011 (COSLA, 2011):

There are currently 1,163 main applicants (amounting to 2,425 people) who are in receipt of full support.

There are 18 applicants (amounting to 39 people) who are not accommodated by the United Kingdom Border Agency (UKBA) and who only receive subsistence support.

A total of 301 main applicants (amounting to 443 people) in Scotland are in receipt of Section 4 Support.

Almost 60% of all AS in Scotland are nationals of just five countries: Peoples Republic of China (30%), Pakistan (11%), Iran (7%), Nigeria (6%) and Iraq (5%).

Research carried out by Wren (2007) estimates that approximately 10,000 AS and refugees (made up of 70 different nationalities) were living in Glasgow in 2003. The majority of these individuals had been accommodated through the dispersal policy. Lack of official statistical data on the AS and refugee population across the UK makes arriving at an accurate figure difficult. As Wren (2007) notes, NASS figures do not include those not receiving NASS support, and those using services suggest a higher number. The increase of AS within Glasgow has resulted in a 60% increase in the BME ethnic population in the city (Wren, 2007).

2.7 Current Data on HIV in Scotland

A recent report by Health Protection Scotland estimates that there are currently 4,033 HIV-positive people living in Scotland, of which 3,339 are attending specialist care and treatment (HPS Quarterly Report, 1 June 2011). The cumulative total of HIV-positive people in Scotland is now estimated to be 6,696, of which 72% are male and 41% are presumed to have been infected outside Scotland (HPS, quarterly report 1 June 2011). The level of estimated undiagnosed cases of HIV across the UK raises risk of transmission and makes it difficult to treat the disease. Research indicates that, in comparison to any other group within the UK, African men are at a greater risk of contracting HIV (Health Protection Agency, 2008). Within a Scottish context, the highest prevalence of HIV in both sexes is amongst those who have risked exposure in sub-Saharan Africa. "HIV infection in the non-IDU heterosexual population living in Scotland remains, for the most part, imported as a result of individuals moving to Scotland from countries where there is a high prevalence of HIV, notably sub-Saharan Africa" (HPA, Weekly Report, 23 February, 2010).

During the first quarter of 2011, there were 90 newly diagnosed cases. It is believed that 33 of these cases were transmitted via males having sex with



males (MSM), 29 via heterosexual sex and 12 were transmitted abroad, while 24 cases remain undetermined (HPS, Quarterly Report, 1 June 2011). The cumulative number of AIDS cases is now 1,640, of whom 1,287 (78%) are male and 1,036 (63%) are known to have died. The number of newly diagnosed cases has dropped significantly from the previous quarter, where 360 cases were recorded (HPS, Quarterly Report 23 February 2011). What remains unclear is the number of AS who are HIV positive.

Souley et al. (2011) note that the risk of HIV transmission from individuals who have been infected abroad is a growing concern. As a result, the HIV Action Plan Scotland 2009-2012 was developed by the Scottish Government to cover both prevention and treatment. This plan incorporated feedback from those living with HIV and highlights the Government's commitment to monitoring of those at highest risk (namely MSM and individuals from higher prevalence areas) and reviewing interventions (Souley et al., 2011; The Scottish Government, 2008). Nevertheless, there are no specific policies on how to support HIV-positive African or AS communities (Souley et al., 2011). BME communities have different ways of coping with health and social difficulties that are often not understood by many statutory and voluntary organisations set up to support them (Souley et al., 2011).

There are, however, a number of actions which the government is already implementing regarding African community groups in Scotland. In the HIV Action Plan Scotland 2009-2012, there is strong commitment from the Scottish Government to improve the existing surveillance systems involving MSM and persons from areas of higher prevalence, particularly African countries. The HIV action plan is committed to accurate detection and/or estimation of new HIV transmissions and the ability to evaluate the impact of interventions designed to prevent high risk behaviour and HIV infection (Scottish Government, HIV Action Plan in Scotland December 2009 to March 2014, November 2009). These actions will provide a clear picture of the HIV epidemiology within MSM and African people particularly in Scotland, and will provide guidance on future interventions.

2.8 Asylum Seekers and HIV – Policy and Practice in the UK

It is worthy to note that there exists a tension in the way that EU/Human Rights legislation at an international level fits with UK policy at a national level (Bowes et al., 2009) and at the local level. At the heart of this sits the ethical dilemma of care and control. For example, Morris (1997, 2002 as cited in Bowes et al., 2009:26) draws attention to competing demands of economic competitiveness and 'welfare protectionism'. Within a Scottish context, the Scottish Government is responsible for devolved matters (including AS integration, housing and social services) and central government is responsible for legislation related to AS and human rights. This can create tensions, particularly as different agencies can be underpinned by competing ideologies. For example, the Scottish Government and the NASS have been described as having competing priorities and agendas (Bowes et al., 2009). NASS is UK Home Office based and has a greater surveillance/controlling role, whereas the Scottish Government advocated for a more integrative approach (to supplement the existing shortfall in labour; Bowes et al., 2009).

Over the last decade, immigration policy within the UK has become more concerned with the control element. For example, in 2000, a UK policy of dispersal of asylum seekers was introduced. This was heavily influenced by a series of moral panics created by the media and a desire to spread the cost of care (Creighton et al., 2004; Bowes et al., 2009; Dawson, 2006; O'Mahony and Sweeney, 2010). Despite there being a lack of statistical data specifically relating to the impact on HIV-positive AS, many of those dispersed were from countries with a high prevalence of HIV/AIDS (Creighton et al., 2004). The dispersal policy resulted in a considerable increase of AS living in Scotland, particularly Glasgow (Bowes et al., 2009; Kelly, 2000, 2002; Wren, 2007).

The dispersal policy introduced by the 1999 Act offered AS no choice in where to live. For many, this has resulted in reduced levels of service provision and increased their experience of racism (Briskman and Cemlyn, 2005; Dawson, 2006). Moreover, it has denied many AS the right to respect for a 'private and family life' (article 3 of the UNHCR; O'Mahony and Sweeney, 2010). For



example, Humphries (2004) notes that this coercive system can lead to AS being displaced far away from family members and social networks of support. When the dispersal policy was implemented, many AS were given less than two days notice, and failure to comply could result in withdrawal of financial, legal and practical supports (Creighton et al., 2004). Additionally, the policy failed to consider expert medical and professional opinions on the negative health implications for those affected by HIV.

Research indicates that in a number of cases the policy of dispersal is believed to have resulted in lower resistance to HIV and encouragement of avoidable transmission (Aspinall and Watters, 2010; National AIDS Trust, 2006). When doctors were asked of their practical experiences in dealing with the dispersal of HIV-positive AS in England, a number of key concerns were raised. For many it was felt there was inadequate transfer of care, due to people being dispersed at short notice, there being no formal arrangements in place prior to the move and a lack of medical staff/support services available at receiving centres (Creighton et al., 2004). Johnson (2003) noted that some private accommodation providers were not providing AS with adequate information on how to access healthcare. There remains a lack of specialist services/support with interpretation, and some GPs were reluctant to accept AS due to additional costs. Additionally, delays by NASS in issuing healthcare certificates made accessing free medical and dental provision problematic (Johnson, 2003). Free prescriptions are vital for those who are not given the opportunity to work and generate income.

Doctors have raised concerns over the impact of interruption to antiretroviral (ARV) therapy and indicated that they had experienced individuals being dispersed despite medical advice given to the contrary (Creighton et al., 2004). Thus, barriers to a positive experience of dispersal include short notice, failure to transfer medical records, failure of decision makers to consider expert advice and lack of attention paid to the resource availability of receiving centres (Creighton et al., 2004; National AIDS Trust, 2006). Consequently, there have been instances in which ARV therapy has been interrupted, HIV has been transmitted from mother to child, and people have consequently died (Cherfas, 2006). Negative experiences of dispersal were discussed by Sinyemu and Baillie

(2005). They interviewed 10 AS currently living with HIV in Scotland. All had been dispersed from London without any choice and felt their current service provision was less adequate than supports they had accessed previously. Gazzard et al. (2005) argue that NASS should have a legal obligation to take into consideration medical reports prior to any dispersal decision being made and to ensure that AS are only dispersed to areas where services are in place to meet their needs.

Cherfas (2006) notes that agencies that support AS and refugees in accessing services remain under-resourced and inadequately funded. Furthermore, Bowes et al. (2009) and Dawson (2006) draw attention to the negative public attitudes many AS have experienced within the community, the concentration of AS in deprived areas and a lack of information about where they could be living and what supports they could access. This has resulted in many fearing assault, feeling unsafe and having difficulties coping with feelings of loss and isolation (Bowes et al., 2009). Cohen (2003, as cited in Humphries 2004:101), describes the NASS scheme and the dispersal system as “the creation of a modern poor law”. A major flaw in dispersing people to new locations where there have been historically been low numbers of AS, is that without strategic planning, services lack expertise and resources. For instance, in 2003 it was estimated approximately 75% of HIV-positive African born people were living in London (Cherfas, 2006). Dawson (2006:14) highlights that most specialist services for AS remain concentrated primarily in London and argues, “The national dispersal program is an act of social engineering too far”. Research indicates there are increased numbers of HIV-positive AS who are unwilling to request accommodation because they are fearful of being moved from London, where they are able to access specialist medical and informal supports (Fekete, 2003).

A report by the National AIDS Trust (2006) found that 78% of clinicians believed dispersal should be delayed if HIV-positive AS were also experiencing mental health problems, and 84% believed that HIV-positive female AS with young children should be candidates for delay. Additionally, 81% believed the notice period did not allow sufficient time to arrange appropriate medication for both



travelling and arriving in a new area (National AIDS Trust, 2006).

In 2005, in acknowledgement of the concerns raised, NASS amended its policy in relation to dispersal. NASS concluded that for future cases, consideration would be given to delaying dispersal for HIV-positive AS. clinicians must be satisfied that appropriate arrangements are in place to ensure continuity of care, and accommodation providers must take responsibility for ensuring that HIV-positive AS are registered with GPs (National AIDS Trust, 2006). Additionally, it is believed that negative attitudes toward AS and refugees in Scotland were reinforced by poor communication from local authorities, and there is now greater awareness of the need to adequately prepare communities (Bowes et al., 2009; Sim and Bowes, 2007). Wren (2007:396) argues that in Glasgow, "Smaller community organizations and voluntary agencies have been able to play an integral part in community development work with asylum seekers in a way which promotes social cohesion in communities where they have been dispersed". Research suggests that dispersal has resulted in a positive experience for some AS. For example, some AS spoke about making friends within the community, their children attending good schools, feeling safe and being able to access good healthcare (Bowes et al., 2009; Sim and Bowes, 2007). Nevertheless, these experiences are despite, rather than because of, national policies that support AS and refugees. For many other AS and refugees, the experience has been harmful.

Most EU countries have a legal duty to treat patients affected by HIV. However, the recent charging system introduced for secondary care in 2004 highlights methods used to restrict access to medical care. This policy has major legal and ethical implications. Since refused asylum seekers are not entitled to free secondary care, many are expected to pay for HIV/AIDS treatments beyond initial testing/diagnosis. However, this is impractical, because as AS they are often not allowed or able to work (Norredam et al., 2005). Moreover, this policy has led to inconsistencies in treatment and resulted in many being denied their fundamental human rights (Clarke and Mytton, 2007; Davies, 2006). For example, Cherfas (2006) reports that confusion over eligibility, unnecessary demands for legal documentation, reluctance of practitioners and a lack of

awareness over entitlement have resulted in some AS remaining unregistered and failing to access primary health care.

Norredam et al. (2005:288) cite Britain as one of the countries imposing increasingly restrictive measures on failed AS, yet ironically, failed AS include persons who cannot return to their countries of origin because their countries are deemed unsafe by UNHCR. This change in legislation means that while refused and undocumented AS are unable to access specific treatment for HIV, they can be treated free of charge for other STI's and communicable diseases such as TB (Davies, 2006). Accordingly, many have been placed in astonishingly inhumane and life threatening situations. For example, there have been instances in which pregnant AS women infected by both HIV and TB have been treated free of charge for TB but had to cease treatment for HIV and place the lives of their unborn children at risk (Davies, 2006). A written submission from the Terrence Higgins Trust, cited in Fortier (2003:20) states that this circumstance "creates a 'cat and mouse' situation whereby someone is constantly in a state of crisis about their severe ill health and where, inevitably, their immune system is fatally weakened and their longevity shortened". Additionally, evidence suggests that individuals who are unable to access HIV treatments are less likely to get tested (Davies, 2006). This increases the risk to wider public health, because there is less chance of diagnosis and access to early treatment. It also makes treatment of HIV more expensive in the long term and increases the chance of HIV-related illness and death (Fortier, 2003). Davies (2006) draws attention to the benefit of providing free ART from both ethical and financial perspectives, since treatment decreases the chance of repeated hospitalisation at a later date. The National AIDS Trust (NAT), cited in Joint Committee on Human Rights (2007), note that the cost to the NHS of a few days of intensive care can equal that of a year's supply of ART.

A recent review of HIV Scotland's experiences with Africans living in Scotland exemplifies the problems faced by AS as a result of UK policy and legislation. Those who were interviewed expressed concern over refused AS being denied access to secondary care, problems associated with cashless support and restrictions on working legally (Souley et al., 2011). Many AS and refugees are



unable to even access primary care due to difficulties in finding GP's who are willing to register them (Joint Commission on Human Rights, 2007). Lack of access to adequate medical care in detention centres, lack of employment to match expertise, lack of awareness/power to be able to enforce their rights and insufficient legal advice were cited as creating further difficulties (Souley et al., 2011; Burnett et al., 2010). Current UK policies increase social isolation and destitution for AS and refused AS and refugees. Moreover, they reinforce the cycle of blame within wider society, they fail to address culturally sensitive needs and they exacerbate the stigma/discrimination faced by AS living with HIV (Souley et al., 2011; Humphries 2004).

2.9 HIV and Vulnerability

Davies (2006:12) argues, "Respect of human rights is essential for effective response to HIV/AIDS, as infringements of human rights lie at the heart of marginalisation and the creation of vulnerability". He goes on to note that the primary risk factors for AS and refugees are social and relate to "poverty, powerlessness and social instability" (Davies, 2006: 26).

HIV disproportionately affects marginalized groups, and the risk of transmission is known to be greater in situations of poverty and inequality (Cherfas, 2006). Large numbers of AS and refugees travel from poorer countries where there is a high prevalence of HIV/AIDS. Additionally, they have individual experiences of persecution, conflict and human rights violations. Consequently, they are especially at risk of contracting HIV. The instability and destitution many experience upon entering a new country heightens risks and increases their vulnerability. Dodds et al. (2004), as cited in Cherfas (2006:4), highlight that the status of asylum and HIV results in them being "doubly stigmatized". Consequently, the hostile attitudes perpetrated by political discourse and media sensationalism have ensured that AS living with HIV have become one of the "most marginalized populations" (Cherfas, 2006:4).

Policies which lead to poverty and insecurity place significant amounts of stress on AS and refugees and impact on their physical and emotional well-

being (Crawley et al., 2011). This compounded with previous experiences of loss, grief and trauma makes AS more vulnerable to physical/mental health issues and exploitation (Sinyemu and Baillie, 2005). For example, in looking at differences between the needs of AS and British patients attending an STI clinic, Rogstad and Dale (2004) found that AS were more likely to require interpreters, to report instances of sexual violence and to require counselling. Additionally, research by Phillimore (2011) found that in areas where there is a high concentration of migrant populations, AS and refugees have difficulties in being able to locate and register with a GP. Low or no income migrants experience a wide range of challenges that result in many being denied the care or treatment they need. This has major consequences for AS and refugees and wider society (Phillimore, 2011). Conversely, creating a system that is proactive rather than reactive to addressing individual health needs is likely to avoid unnecessary costs at a later date.

Morris (2005) draws attention to the issue of HIV/AIDS within refugee populations and the significant power structures that increase risks of transmission for displaced populations. Many AS and refugees arrive in Britain after experiencing high levels of trauma, torture, conflict and abuse (Anderson, 2008; Humphries, 2004). This can have a significant impact on social, emotional and cognitive systems. Consequently, they are at greater risk of experiencing mental health problems, such as depression and post traumatic stress disorder (Aspinall and Watters, 2010). For those that have endured such painful experiences, the dispersal policy can exacerbate existing psychological and emotional distress. For instance, having to describe difficult and traumatic experiences to a range of new health professionals is hardly therapeutic (Weston, 2003 as cited in Cherfas, 2006). Crawley et al. (2011:5), point out that fear of deportation may lead AS to avoid seeking medical care, and they are thus at higher risk of receiving a late HIV diagnosis (Cherfas, 2006).

AS and refugees are regularly and falsely accused of coming to Britain to access health services (Attawell, 2009; Bowes et al., 2009; Cherfas, 2006). Crawley (2010) reports that there is no evidence to suggest this, and the majority of those seeking asylum have little choice in their destination, as it is usually decided by



agents or other individuals. This combined with social barriers (such as stigma and discrimination) can prevent those in need from seeking crucial supports. Norredam et al. (2005) note barriers that migrants have in accessing health care, such as language, culture and lack of information. For AS and refugees, these difficulties are enhanced by punitive and lengthy policy processes in determining status. As described earlier, current policy rhetoric within the UK results in AS being kept in situations of poverty and powerlessness, which in turn exacerbates their vulnerability to HIV/AIDS (Bettinson and Jones, 2007).

Clarke and Mytton (2007) note that AS and refugees experience social problems that can exacerbate health problems associated with HIV and/or increase the risk of transmission. These include poverty, overcrowding, lack of knowledge of health systems, language barriers, negative public attitudes and dispersal to areas that lack appropriate information on the needs/rights of AS. Moreover, research indicates AS can be reluctant to be screened for HIV for fear of deportation (Clarke and Mytton, 2007). This circumstance is potentially life-threatening, because it prevents early diagnosis and treatment. Crawley et al. (2011) draw attention to the destitution experienced by failed AS and the coping strategies they use in order to survive. Many are unaware that they are entitled to free primary healthcare and are prevented from accessing any form of support for fear of deportation. Thus, social relationships become central to existence. This includes forming sexual relationships with local people and selling sex in exchange for cash, goods and/or shelter (Crawley et al., 2010; Cherfas, 2006). These relationships can be exploitative and disempowering for AS and can increase the risk of HIV infection.

Kennedy and Rogers (2009) note the western cultural norms that are often assumed when delivering programmes designed to support people affected by HIV within the UK. The inclusion and participation of a group of AS and refugees from sub-Saharan Africa challenges these assumptions and highlights the fact that current services often omit the specific needs of HIV-positive AS and refugees. For instance, the individualised approach towards self-care does not consider the relevance of spiritual beliefs and group participation in establishing a positive sense of identity that is often found in African culture

(Kennedy and Rogers, 2009). Additionally, programmes which emphasise personal responsibility and choice are likely to have limited impact for those who have few opportunities to exercise these.

Research by Ndirangu and Evans (2009) explored the experiences of African immigrant women living with HIV in the UK. Their findings indicate that their ability to cope is influenced by their legal status and individual/cultural experiences. Whilst Church and their own faith offered support in dealing with difficulties of living in a new city, stigmatisation stopped many from accessing services to help them cope specifically with HIV (Ndirangu and Evans, 2009). For these women, HIV status has high social costs, particularly as many African communities heavily stigmatise HIV-positive women. All the women interviewed thought society perceived women with HIV as immoral or prostitutes and believed that AIDS was “their fault” (Ndirangu and Evans, 2009:111). Additionally, without exception, all of these women had been too fearful to get tested and only did so upon the advice of health professionals. The result was that all received a late diagnosis once in the UK. The stress placed on these women in trying to support themselves and their families (both in Britain and at home) took precedence over their own health needs (Ndirangu and Evans, 2009). Additionally, not being able to work had a significant impact on their sense of self, which reinforced feelings of low self-esteem, lack of purpose and social isolation ((Ndirangu and Evans, 2009).

For many AS and refugees living with HIV, the predominant concern is fear of disclosure and stigmatisation (Cherfas, 2006; Fortier, 2003). HIV remains linked to dishonourable behaviour in many cultures, and there is a real concern of being abandoned by friends, family and community members. These fears are not unfounded, as many AS and refugees have reported instances of being banished from the lives of people they were close to (Doval and Anderson, 2003, as cited in Cherfas, 2006). Conversely the anxiety created by fearing others will find out about the diagnosis can also lead to increased social isolation (Kang et al., 2003, as cited in Cherfas, 2006). AS and refugees rely heavily on wider community supports due to the daily struggles created by their social status. Accordingly there can be little informal, formal and



emotional support available for AS and refugees in coming to terms with and learning to live with an HIV diagnosis (Cherfas, 2006). Stigmatization is also experienced from wider society, as political discourse and the media reinforce negative stereotypes and prejudices depicting AS and refugees as being a danger to the public health (Cherfas, 2006; Fortier, 2003). Davies (2006: 34) argues that the notion of “health tourism” is “an illusory concept, perpetuated by the UK media and Government”. Fortier (2003) draws attention to negative media representations that depict AS and refugees as being in a high risk HIV group, thus potentially contagious and threatening. This serves to drive fear of being in contact with people affected by HIV and reinforce discrimination associated with the disease. The regular experiences of both direct and indirect discrimination can be psychologically damaging for AS and refugees, reducing the likelihood of them seeking support and being tested (Fortier, 2003). Stigma prevents AS and refugees from accessing services, disclosing HIV status and “enjoying the same rights and freedoms” of those not affected by the disease (Davies, 2006:30). Consequently, stigma associated with HIV is one of the main barriers to preventing the spread of the disease and ensuring that individuals receive adequate treatment.

2.10 Conclusion

In summary, a complex combination of cultural, social, legal, institutional and structural barriers prevent asylum seekers and refugees living with HIV from successfully accessing adequate healthcare (Cherfas, 2006). Legal obstructions (such as denial of legal status, dispersal policies, lack of consistency regarding rights to healthcare), language barriers, stigma, marginalisation, social exclusion, religious beliefs, fear of discrimination, cultural attitudes, inconsistencies in services delivery and lack of information regarding the number of AS population affected by HIV act as deterrents and thus contributes to HIV vulnerability (Attawell, 2009). Having to seek asylum places AS and refugees in a position of vulnerability in itself, and health, particularly preventative care, is often not a priority (Cherfas, 2006). Additionally, tackling negative social attitudes, which are often enhanced by negative media attention, remains a key challenge (Attawell, 2009). Negative perceptions of rising numbers and costs associated

with those seeking asylum has led to asylum seekers and refugees experiencing high levels of verbal and physical abuse, yet the reality is the number of people claiming asylum has reduced considerably (Aspinall and Watters, 2010). Cherfas (2006) suggests that if the health needs of asylum seekers are to be met, practitioners must focus on both past and current experiences that could be contributing to psychological distress, including the lack of control, instability and positions of powerlessness enforced upon them within the UK.



Chapter 3: Methodology

3.1 Introduction:

Researching vulnerable, hard-to-reach population such as HIV-positive asylum seekers brings a number of complexities, challenges and dilemmas to the fore. Many HIV positive asylum seekers – and in particular those whose applications have been refused – are unwilling to engage with people outside of their known support systems. Accessing HIV-positive asylum seekers for interviews was fraught with uncertainty and at times limited success. In order to understand the complexity and uncertainty that marked the lives of HIV-positive asylum seekers, it was important to choose research methods that would be inclusive and participatory, allowing flexibility and openness for participants to tell their stories.

3.2 Qualitative Research Design:

The study was designed to gain a deeper understanding of the experiences that HIV-positive asylum seekers faced since being dispersed to Scotland, with a particular focus on human rights issues. Given these complexities, a qualitative research design was adopted that helped to construct a narrative of the lived experience of HIV-positive asylum seekers. Shank (2002) defines qualitative research as a form of systematic empirical inquiry into meaning. Denzin and Lincoln (2000) point out that qualitative research involves an interpretive and naturalistic approach, studying people in their natural settings, attempting to make sense of, or to interpret, phenomena in terms of the meanings people bring to them. Incorporating a phenomenological approach helped illuminate the lived experiences from the perspective of the research participants. Such phenomenological approaches are based on subjectivity and help to understand personal knowledge and emphasise the importance of personal perspective and interpretation of lived experiences from the participants' own perspectives. The qualitative research design helped in exploring and understanding the HIV-

positive asylum seekers' perspectives and experiences in their own words and allowed an exploratory and descriptive analysis that stressed the importance of context, setting, and the respondents' frame of reference (Marshall & Rossman, 1995).

3.3 Sample:

Given the sensitive nature of the study, identifying participants was a long drawn process. We began by contacting the two key HIV organisations in Scotland with whom we had prior established links: Waverley Care and the Terrence Higgins Trust (THT). The large majority of the sample emanated, however, from Waverley Care's African Health project in Glasgow, which provides support to HIV-positive people, the majority of who come from sub-Saharan Africa. In total, interviews were held with 19 HIV-positive Black African asylum seekers (15 women and four men). Five of them were classified as refugees, having been granted refugee status just prior to the interviews. The nationalities of the participants varied; though a significant number came from Zimbabwe (8, n=19), others were from Ivory Coast, Burundi, Ethiopia, Malawi, South Africa, Nigeria, Tanzania and Kenya. All participants lived in Glasgow and received support from Waverley Care's African Health Project. However, some of them were also service users at THT and introduced to the researchers by THT.

3.4 Data Collection:

The field work for collecting data was complex and time consuming. Data collection began in June 2010 and lasted until May 2011. Because participating in the study might have imposed a financial burden on these participants, all study participants were compensated for their time and travel cost.

3.4.1 Interviews:

Using an open-ended research schedule, in-depth interviews were held with individual respondents. These were generally held in the premises of the Waverley Care African Health Project or at the homes of individual respondents,



and a couple were held in THT's Glasgow premises. However, many interviews were also held in the not-so-conventional venues such as the researcher's own automobile or in a quiet café, as a convenient place was hard to come by at times. It was very evident from the outset of the study how difficult it was to gain access to this otherwise hard-to-reach population, particularly since some of the respondents were failed asylum seekers and were forced to lead a somewhat fugitive existence. At such times respondents, understandably, wanted the interviews to be held only in the office premises of the African Health Project. Ensuring anonymity and protecting the identity of the participants were central to the research process at all times.

Data was collected through 19 individual interviews, which were helpful not only in exploring some of the complexities of life as an HIV-positive asylum seeker, but also in building a relationship of trust and rapport between the researcher and the researched. All interviews and the focus groups were digitally recorded and transcribed.

It was telling that the majority of respondents in the study were very vulnerable and were living a hard life in Scotland. They were helpless and some homeless and faced unpredictable situations in their everyday lives. Given the sensitivity of the research, most respondents' participants were keen to meet with the researcher away from their place of residence. Most of the interviews, as mentioned above, took place at the African Health Project. However, the unpredictability of participants' lives necessitated a need to go with their flow and be flexible about time and location of the interview. This led to the interviews taking place sometime in a café (as no other suitable alternative venue was available), or in the researcher's own automobile. Moreover, almost all the interviews took place in the evenings or weekends, to fit with the availability of participants. Many interviews had to be cancelled and rearranged several times at short notice due to unpredictable situations in their lives. Some of the interviews lasted over 2-3 sessions.

3.4.2 The focus groups:

Two focus group meetings were held, with a total of thirteen and seven participants respectively. The majority of these respondents had also been interviewed individually; there were, however, a few respondents who only participated in the focus groups. One might question whether conducting focus groups with the same respondents were useful and whether they brought any additional value to the research. Our experience was that in fact, the focus groups, particularly the larger one (with 13 participants), were extremely powerful, poignant and effective in communicating issues, providing much deeper insights and rich data. Interaction with each other sparked brought out new information and thoughts for discussion. However, what was most remarkable was that these focus groups gave individuals who shared a common affliction, destiny and heritage a space to support and encourage each other to tell their stories and to open up at a deeper level, in a more intense manner, because they had each others' support. The ease, security and palpable sense of shared humanity experienced by the respondents was reflected in crying, singing, laughing and praying together as they narrated their stories. Also, having spent time, with the researcher through the individual interviews provided for more trust and ease to share more freely and to allow the floodgates of emotions to be opened. Ultimately, these focus group meetings acted as cathartic group therapy sessions.

3.5 Ethical Framework:

While utilising an effective research design and methodology is a priority in all research, a transparent and strong ethical framework is crucial for the current endeavour. Formal ethical approval for conducting the study was obtained from the Research Committee of the School of Social and Political Science, University of Edinburgh, before commencing the interviews. However, for research of this nature the more formal procedures need to be enhanced by a conscious and rigorous value-based ethical framework. The values that underpinned this research were those of respect, honesty, reciprocity, empowerment, engagement and voluntarism. They guided the researchers at all times through the process.



3.6 Complexities and Challenges of interviewing HIV-positive asylum seekers:

Interviewing individuals who are marginalised, stigmatised and vulnerable involves varied complexities and challenges. These are summarized under the subheadings below.

3.6.1 Complexity of the context:

The study involved interviewing HIV-positive asylum seekers, who are some of the most marginalised people in the world. They are often stateless and may have no legal recognition in their host countries, uncertain immigration status and no or limited access to state benefits or employment opportunities (Davies, 2006). The lived accounts of all the participants in the current study resonated with these realities. In addition, several of the participants had experienced abuse, violence and threat to their lives, leading them to flee for their safety and seek asylum elsewhere. Away from their own country and family and friends, they found themselves in a strange world, often revisiting and reliving their painful experiences during the interviews.

3.6.2 Complexity of the topic:

Central to the study was an attempt to develop an understanding of human rights issues vis-à-vis the HIV-positive asylum seekers who were living in Glasgow following the dispersal policies of the UK government. Many respondents found the notion of human rights as understood in the West rather difficult to grasp; their own lives were marred by an absence of basic human rights and many lacked an understanding of what it means to have basic human rights. Some respondents assumed a powerless and 'learned helplessness' position and therefore it was a challenge for the researcher to explain to the participants the importance of the study.

3.6.3 Complexity of telling their stories:

The stories of the majority of respondents reflect the pain and stigma and psychological scars that each participant had endured as a result of the violence and abuse suffered in the native country. While telling their stories proved cathartic for some, others seemed to have a very flat presentation, with low mood and emotion; their sufferings have been so cruel that they presented as if nothing mattered to them. Some others felt a need to show the researcher the injuries that they had sustained from gunshot wounds and gang rape, leading to one respondent having sudden high blood pressure and having to stop the interview.

3.6.4 Complexity of environmental factors:

The complexity of interviewing a hard-to-reach population is further compounded by the fact that some of the participants had no fixed abode. This was particularly true in relation to those asylum seekers whose applications and appeals were rejected by the UKBA and who were supported by some kind-hearted host families; which necessitated such participants having to seek permission before attending the interview.

3.6.5 Complexities related to the interviewer's status:

The interviewer's role as a woman: was crucial to the success of the data collection. A majority of the participants were women who had experienced some form of trauma at the hands of a man. This was perhaps the reason, in part, that none of the female respondents were willing to be interviewed by a man. Consequently, the majority of the interviews were carried out by Dina, who was known to some of them through a previous study of children affected/infected by HIV (Cree & Sidhva, 2010). However, the focus groups were conducted jointly by George and Dina. The women in the group were happy to be part of a mixed group that consisted of both male and female service users, project staff and researchers.



3.7 Data Analysis:

The data analysis provided an opportunity to portray the lived experiences of HIV positive asylum seekers, such that their experiences were presented as accurately as possible, to preserve the richness and uniqueness of the data. The analysis of data began with the transcription of interviews. This led to the development of certain themes and categories that summarised the findings, as illustrated in the chapter that follows.

3.8 Conclusion:

Despite the complexities involved, the real strength of this relatively small research project is that it helped to give voice to a group of individuals who live on the margins of our society. The study design provided these participants with an opportunity to tell their stories and have their voices heard. The next chapter presents the findings from the study, giving details on the many challenges and hardships faced by these vulnerable individuals.

Chapter 4: Findings

4.1 Introduction

Through the individual and focus group interviews, respondents were encouraged to share their thoughts and feelings in four topic areas: why they came to the UK, the experience of seeking asylum in the UK, their experience of being an HIV positive asylum seeker in the UK, and their hopes for the future. The findings from the interviews are explored under these four topic areas.

4.2 Findings

4.2.1 Coming to the UK

I. Reasons for Leaving

Fleeing violent situations, being in search of treatment, being a victim of human trafficking and overstaying on a student visa were cited as the four reasons why respondents left their countries of origin and came to the UK.

A significant number of the respondents (12, n=19) left their native country because of some form of violence that they or their close family member/s had experienced, were experiencing or were in fear of experiencing. Respondents spoke about fleeing violence that was either engineered by tyrannical political regimes or violence that was perpetuated through a personal relationship.

Fleeing a tyrannical political regime and politically motivated atrocities

One respondent from Zimbabwe described the routine terror and panic created by the ruling party and told how she was forced to flee from her country because she feared for her life. She described her situation at length.



I came for my safety because Zimbabwe was politically very unstable. I was in danger of becoming a victim of violence in the sense that I was put in a spotlight through my work with the Zanu PF. I used to be forced to attend meetings and to name who your neighbour is, their names and children and make sure that they come along to meeting. We knew that if we did not attend these meetings, we were in big trouble ... we were seeing things around us, people being beaten, people disappearing. So at the end of the day, if you have a conscience, you are worried when are you going to be the person who points a finger at somebody and at the end that person will not be seen, or when will it be that the other side will finger me and 'she's the one' and then I am a victim with my children. I became that tense I could not take it. I was not knowing what could happen. I remember one time I did not attend a meeting and they actually came to my house, knocked on my door; fortunately I was alone in the house...I could not even go to the toilet for fear if they see me what will happen...even breathing was a problem, that's how scared and terrified I was and that's when I decided that I needed a way out.

Another woman from Uganda, whose father and brother had been vocal against the ruling regime, left her two young children with a friend because of a perceived threat to her life, after her father disappeared and her brother was murdered. She said,

I left to save my life. My brother was forced to drink poison and he was killed that way...I thought, if I am to survive I will need to run away for my safety.

One woman spoke about the continuing horror and nightmare that she has lived through for almost a decade after she was raped in front of her son by the supporters of the ruling party, which she did not support. She spoke about the humiliation and pain of being gang raped in front of an adult son and how that gave her the strength to flee her country.

Back home there was violence between parties just before the elections and I was at home with my big son and they just came in to my home and raped me in front of my son, so I decide to run away from my country...oh it was a terrible

experience...my big son tried to protect me, but he was beaten when he was trying to help me ...they hit him and knocked his two teeth out.

Fleeing personal/familial gender-based violence and abuse

The narratives of three women focussed on the gender-based violence that forced them to leave their homes and seek asylum in the UK. They referred to the maltreatment they had suffered just because they were women: being beaten by their husbands or partners, being raped with impunity, and being ritually mutilated. One woman from Malawi spoke about the constant abuse and violence she experienced from her husband because she did not get pregnant with her husband. She said,

Things became so bad one day that he chased me out of the house naked. My Pastor brought me to here on a visitor's visa to get a break ...but I decided never to go back there, because I could not go back to that living hell...I would rather live here with all the problems than go home to him.

UNAIDS (2010) has pointed out that factors such as conflict, war poverty, trauma and powerlessness make asylum seekers more vulnerable to HIV/AIDS.

II. Victim of human trafficking

One respondent, fleeing a marriage to a much older abusive man, migrated to the UK in expectation of a well-paid nanny's job, only to find herself forced into sex work under exploitative conditions. She spoke about her shock, misery and suffering as a 17-year-old teenager who was compelled into sex work in a country where she was a stranger. She said,

When I came to the UK, I came with many dreams, but that was the hardest, most difficult terrible time of my life.

UNDP (2007) states that trafficking of women and girls is a gross violation of human rights, and the factors that increase a woman's risk of being trafficked are also the factors that increase her vulnerability to HIV.



3. Seeking treatment

Two respondents came to the UK to seek treatment for non-HIV related issues. Both women were unable to access appropriate treatment in their countries of origin because of their political affiliations.

One woman from Zimbabwe told the interviewer that she came to the UK to access treatment after being shot in her leg and gang raped. She became very emotional when she recalled the horrific gang rape that she had experienced by political party thugs, to a point that the interview had to be stopped on that day. She said that, had she remained in Zimbabwe, her leg would have been amputated, as the hospital was not willing to offer her any other treatment because of the unwritten support and allegiance they owed to the ruling party. She said,

I was dumped on the roadside and lay there for hours before I was hospitalised. I do not know who took me there...I was very confused; I was in coma, so I don't remember everything that I went through. I came with my cousin in Ireland, so that I could get treatment. My leg became so bad that they were talking about amputating it...I knew that my only chance was to try and get some proper treatment.

4. Becoming 'overstayers'

Two respondents came to the UK as students and overstayed after their visas ran out, when they discovered that they were HIV positive. One woman from Nigeria told the interviewer that once she had discovered she had HIV, her husband deserted her. She explained that there was no way she could go back home because she feared the reaction of her family, as she had married against their wishes. Equally, she was terrified about the prospect of not having money to buy prohibitively expensive medication. She said,

My father is already crying because I left them, but, if he found out that I have HIV he would not be able to take it...he would break down completely if I had to suffer without medication in front of his eyes.

4.2.2 Seeking Asylum

Three key areas emerged in relation to the asylum-seeking process: bewilderment and uncertainty about the present and future, issues in relation to the United Kingdom Borders Agency (UKBA), and dispersal and detention.

I. Bewilderment and Uncertainty

All respondents, with no exceptions, described a sense of bewilderment and pervasive uncertainty about the present and the future. They used words such as *extremely stressful, confusing, uncertainty, doubting, worrying, frustrating, limbo, panicking, disoriented, terrified, hellish, frightening, and scared* to describe this stage.

Some respondents were visibly upset when speaking about some of their experiences in relation to seeking asylum. Interestingly, a number of respondents used metaphors from nature such as *the edge of a mountain, a dark tunnel, a deep well and shifting sands*.

One man told the interviewer that he found it difficult to sleep and to eat and that he felt as though he was living on the edge of a cliff. He explained,

It is a very difficult time for me; I feel every time worry and thinking all the time; cannot stop thinking, this and that. I am worrying about me, what about my life in this country, what about me? What the Home Office is going to do with me; how is my future going to be? As if I am at the end of a high mountain and can be fallen down at any moment.

One woman described the process of asylum-seeking as a dark, interminable tunnel with little hope and a sense of pervasive uncertainty. She said rather poignantly,

It's like you have to just keep travelling in the dark...you can't turn back because that is gone too far. There is no place to get off right or left and you don't see no



lights at the end of the tunnel, but you just have to think that your day will come, when you get out of this tunnel which is being an asylum seeker here.

Another woman likened the asylum seeking process to being in a deep well. She said,

You are there not because you wanted to be, but because you had to be ...you are trying to get someone to save you, but they don't even want to hear your cries... they think somehow you deserve to be there. What else can we feel scared about every minute in the present and not knowing, not knowing what the morning will bring and will it come for me?

One woman asked the researcher if she had heard of the shifting sands in Tanzania. She likened the asylum process to the shifting sands that kept blowing you *"further and further, but you don't know when you're going to be able to settle down"*.

Another reaction was anger. One woman started crying and became rather agitated when the researcher asked her to describe her experience of applying for asylum. She said that she had received much negativity, suspicion and lack of sympathy which made her feel angry and a sense of hatred towards herself. She said,

If there was any way, if I had any choice at all I definitely would not be here. I feel so angry all the time and nowadays I hate myself too...

She was not alone in suggesting that the asylum-seeking process had given rise to a sense of anger in oneself. Another woman talked about feeling angrier in the one and a half years since she had applied for asylum than she had in her entire life. She said,

We are treated with so much suspicion that you feel insulted and it goes straight in here (pointing and beating her fingers against her heart).

II. Issues in Relation to the UKBA

A place to fear

The office of UKBA referred to as the Home Office by most respondents, was a place that all respondents, without exception, were afraid of and dreaded going to. One respondent's graphic and detailed account tellingly provides an understanding of the perceptions of individual seeking asylum. She said,

That place was packed full, the air was even stale. The officers tried their best to work as hard as they can, but each person has got a different reason for seeking asylum...there were all sorts of races...we were trying to give each other strength, 'just go and make the report'. But it was that terrifying, my friend, that even some people waited for their number the whole day and ran away at the last minute, they were scared not knowing. Because the first paper we are given say you are a person who is deemed highly at risk of absconding therefore can be deported to your country at any time. That is the first paper you are given when your ID is taken away from you. The first impression is that scary...to gather your guts and say I need help.

One man spoke about the counter-intuitiveness and irony of his fear in relation to UKBA. He said,

Think about it, why are we so scared to hear the name Home Office, this should be the first place of safety for people like us, who are leaving our country and family and children, because we are too scared to stay and are afraid for our lives.

One respondent explained that every week she needed to go to the Home Office to sign to ensure that she received her payment. She said that each week she underwent panic reactions. She likened the panic to the experience one has before an examination. Recently the Home Office had asked that she bring along her three young children too. She said,

Sometimes when I go to the Home Office, I am not sure whether I am going to



come back or they are going to take me in...ever since they have asked me to come with the kids, I wonder are they going to send me to detention ...I get so scared...I shiver with fright...I feel like throwing up and my stomach churns...it is not good I think for me to go this, my viral loads must be going up for sure.

HIV minimised

During the focus group, four participants (both men and women) suggested that they felt that the UKBA made light of their HIV-positive status. One respondent, who has now received refugee status, recalled that in the first five minutes of arriving in to the UK she was told that being HIV positive did not guarantee her asylum. She recalled being surprised about this at that time, but realised later just how true his words were. She said,

I realised that you are not really given any priority because of your sickness...they see HIV as just another problem about you.

One woman told the researchers during the focus group discussion that when she was told that her application for asylum had failed, the officer said,

Oh, you have been alright for the last five years... you know HIV is not going to kill you, you had better make plans to go home".

Respondents feel that the officials do not take them seriously. They also feel misconstrued, neglected and discriminated against.

Lack of understanding of issues in the native country of the Asylum Seeker

Most respondents felt that the UKBA lacked an understanding about the realities in their countries of origin. Some spoke about the Internet being a source of misinformation.

One woman said that even if the information about medication being freely available was true, it was inaccurate, because, in Zimbabwe it was only available

to people who were rich. She said,

All this website Internet are for big people. It is not for people like me from a village... we have to struggle even for some pain medicine.

A respondent recalled a recent discussion with an official who insisted that the President of Gambia had gone on record to say that they were providing medication for all HIV-positive people and that HIV was curable. She said,

How can they believe what they read on the Internet? People are dying because they do not have medications...vomiting, diarrhoea, no proper, enough food.

Another woman from Zimbabwe echoed her sentiments. She said,

With the Home Office you can't discuss anything... there is a big glass window. They insult you by telling you to go home when there is no treatment in my country for people like us. What do they know? If I go home I will be dead, no food, no medicine, no job, no treatment for HIV...they don't know what's going on there really, they twisting you, twisting you, like a hot wire.

III. Dispersal and Detention

Dispersal

Respondents varied significantly in their experiences of dispersal. On one hand, there were those who looked upon it as a routine procedure of being transferred from one location in the UK to another location in the UK, i.e., Glasgow. On the other hand, five of the respondents felt that their basic, fundamental right to family life had been snatched from them as a result of being dispersed.

One woman with three young children spoke about the utter misery she felt being dispersed to Glasgow and separated from her husband. She became extremely emotional when she recounted the impact that dispersal had had on her family. She said,



It's a lot of pressure on me and the children; it's really hard, especially when you have such young children. Sometimes I think it is about how much they can stretch you and how much they can wear you down. How did they have the heart to break up my family, don't we have the right to live together?

Another respondent who had just lost her asylum claim spoke about her misery and daily sadness because she was dispersed to Glasgow, separating her from her daughter and grandchild, who were both HIV positive. She said,

I find it very unbearable to live by myself and am on medication for I cry a lot everyday. I feel helpless, so powerless. How much more can I suffer, I ask my Lord. I am sick and at least my daughter could cook and give me something to eat and I could look after her child when she needed. Now this separation, don't they understand we need to be together to be there for each other, we have no one else in this world. Are they God that they separate us?

The National AIDS Trust (2006) emphasises that that dispersal should not take place when individuals have family members or support networks in close proximity to them. It suggests that a lack of support could create profound problems in child care, isolation, mental health and adherence issues. Given that HIV is still stigmatised, the mental health impact of dispersal should be considered immediately, and adequate preparation time should be offered to the AS. Additionally, the report reiterates the importance of social networks. Sinyemu and Baillie (2005) looked at issues facing HIV-positive Africans living in Scotland. Their findings indicate that many AS who had experienced dispersal were placed in locations with limited community and formal supports for dealing with both HIV and their asylum status.

The literature also suggests that the UK dispersal policy, particularly at short-notice, has impacted on health and well-being of HIV-positive AS (Fortier, 2003), and in some instances increased the risk of transmission (Aspinall & Watters, 2010; Creighton et al., 2004).

Detention

Two respondents spoke about their experiences of detention. One woman's account seemed rather ironic; it reflected the harsh reality of failed AS in the UK. She likened the Dungavel House immigration removal centre to a five star hotel with 'fantastic facilities' and 'fantastic food from all over the world'. She said,

The food is really, really good and as much as you can eat. I was living on a cup of coffee and anything anyone gives me, sleeping here there and this one and that one, I really enjoyed the good food at Dunvangel...it is like a very posh hotel. I really, really liked being in Dunvangel.

Whereas another respondent's narrative was in rather stark contrast—he recounted that he was meant to take medication with specifically prepared meals, yet the routine at detention centres made this problematic. He likened the detention centre to a glorified prison. He said,

It's more like a fancy prison, but you sleep in dormitories. I was unable to manage my treatment there. I was really so wretched and sad. People go around like zombies. Only the doctor can stop and start your medication but they just take you and they don't care; if you have to start and how bad you feel.

Fekete (2003) draws attention to the inappropriate conditions of detention centres in being able to meet the needs of HIV-positive AS. Research suggests detention increases psychological stress, with higher rates of self-harm and suicide attempts being reported (Chantrais, 2011; Robjant, 2011). Moreover, the longer detention periods are likely to increase the severity of mental health difficulties.



4.2.3 Being a HIV-Positive Asylum Seeker

We asked the focus group members what being an HIV-positive asylum seeker or refugee meant to them. The majority of respondents emphasised the immensity of their lives as asylum seekers. They used words such as hurt, pain, grief, isolation, 'just doing nothing', losing friends and family, losing your own culture and about the lack of answers to their many existential questions: why me, why all this, why now?

Among the themes that recurred were there fear of disclosure, being under UKBA surveillance, being a failed AS and the unfathomable asylum system. Access to medical care was also discussed in much depth and with much animation during the focus group, along with the problems respondents faced with the voucher system. Other themes included the pain and shame experienced, experiences of stigma and labelling, the emptiness and the interminableness of their present existence, multiple jeopardy and finally the solace gained from support networks.

I. Fear of Disclosure

An overwhelming majority (13, n=19) of participants in this study had not disclosed their HIV status to any of their family or friends. This was, partly because they were afraid that their confidentiality would be breached and partly because they were afraid of rejection and any other adverse effect associated with HIV disclosure in Africa. This finding replicates Sinyemu and Baillie's (2005) finding in relation to individuals not disclosing their status.

Some respondents spoke about the burden of secrecy and others about the sheer relief of having been able to share their burden. The demerits and benefits of public disclosure have been researched since the first decade of the AIDS epidemic and the paradox of disclosure has been studied in depth (see, for example, Paxton, 2002).

One woman's narrative is representative of the views many other respondents. She said,

The problem we face in our communities, you know when people hear this one is HIV they try to stay away from that person, but tell the news story to everybody, everybody that they can tell. So why tell people and make yourself be shamed?

It is ironic that individuals who have fled persecution or have come in search of treatment to the UK need to then live in constant fear of disclosing their HIV status, to fellow Africans within their own communities or within the more informal social support systems that they have managed to forge in their new host country.

Many respondents did not disclose their status to their family members because they did not want to hurt their loved ones any more than they were already hurt or because HIV and AIDS are still synonymous with an imminent death, and they wanted to protect them from such pain. One respondent said,

What is the sense of making them worry any more about me, my son has seen me being raped in front of his eyes, I would be a very selfish mother to try and put this on him now.

Another woman added,

My sister and brother would be broken if they knew about it; they would cry. They would really cry, because they have been to so many funerals of people who have died from AIDS. They will think that I am going to be dying tomorrow. Yes, that's how scared they will get.

II. Being Under UKBA Surveillance

When respondents spoke about the asylum procedure, they used terms like *confusing, difficult, too complicated, can't understand*. The phrases 'don't know why' and the hard hitting question 'why?' resounded in their narratives: *Why*



did my claim fail? Why do I need to wait for so long? Why can't they at least see what is in front of them? Why can't they just believe me?

Respondents without exception spoke about the UKBA as though it were an all-powerful entity, with extra-human propensities. They referred to it as the Home Office, which is 'neither a Home nor an Office' but some kind of omniscient power, capable of harm and destruction.

One woman, quoted earlier, explained that every week that she needed to go to the Home Office to sign to ensure that she received her payment, she underwent severe stress. She was particularly frightened since the Home Office had asked her to bring in her three young children each week too.

Others spoke about their fear of being taken in to detention without their medication. This caused them severe stress, particularly because non-adherence and changing medical regimes, at will, have some rather serious consequences for some. One respondent said,

You cannot take anything. They just take you...they say you cannot take anything.

Another woman explained,

Sometimes the medication can make you to sleep more and you are scared that they will just come in the morning and knock your door and you have to leave without your medication and then you can be so sick when they release you and your medication has to be changed and all the sick feelings and sicknesses have to be experienced again till your body accepts the new tablets.

Weston (2003) affirms that psychological stress, isolation and anxiety often characterize the process of seeking asylum.

III. Being a Failed Asylum Seeker

Respondents who described themselves as failed (refused) AS were in a particularly vulnerable situation, because they are not entitled to any rights or supports. In fact, they become homeless, with no recourse to any money and are often forced to sleep rough and go hungry.

During the focus group when we asked them how they felt and what their experiences of being a failed AS were, they spoke about feelings of uncertainty, helplessness, powerlessness and discrimination. Respondents were distressed when they spoke about this experience and when others spoke about their experiences.

One respondent spoke about the pain of being labelled as an AS and was rather emphatic as he said,

They think we are scavengers, not humans, but I say we still have blood flowing through our veins and you and me we all have the same colour of blood. We came here to live in freedom, to see the human side of life.

One woman, who had just been served a notice to leave her flat and was rather poorly, wept as she said,

You feel so paralysed; you feel your life is in limbo, no life at all, you have lost everything, everything. Where can I go? What shall I do?

In response to this woman's questions, one woman spoke about how difficult it was not to be allowed to give sanctuary to a friend who had become homeless. She said,

It is very stressful being denied asylum even though you have got HIV positive, it is terrible to see our fellow country people, our fellow African friends being thrown out of their homes and you cannot accommodate them...we will also be victims.



Finally, one woman's narration provided a much required comic interlude to this emotionally-charged conversation in the focus group. She said,

I have been destitute for 6 years and everywhere I go people say to me oh we always see you walking, walking, walking... where are you going to, I am really desperate but I don't talk, I just say oh I am going for a walking!

She also narrated to the group a typical day in the life of a failed AS. She said,

It is hard even my psychiatrist calls me survivor, not by my name. I go one place for my breakfast, somewhere for my lunch, and somewhere else for my supper. Some of these places are very run-down soup kitchens. If you really respect yourself you would not go, but you have to survive and so you have to go. I know where you can get free clothes in Glasgow now, so I take one set, wear it for a few days and then bin it and wear another, because I have nowhere to carry and keep the clothes.

Refugee Council (2004) notes that homelessness, hunger, depression, anxiety and poor physical health are all glaring characteristics of the failed AS experience.

IV. Access to Medical Care

Respondents were very vocal and wanting to have their voices heard. Without exception, the respondents were extremely appreciative and reported positive experience within specialist HIV clinic in Glasgow. They spoke very highly of the humane and considerate treatment they had received. One woman said,

Brownlee people are all caring, considerate and sympathetic. Their support really touches you here (pointing to her heart) and makes you feel that people care, that you matter as an individual.

Another woman from Burundi also emphatically supported the view. She said,

They take care, because they know what we are...and the social workers do their best, they do their best, do their best. But other hospitals are not trained to feel like that.

However, a significant number of respondents were rather dissatisfied with the treatment they received from their GPs, dentists, NHS 24, the ambulance service and the general hospital departments, particularly the Accident and Emergency Departments. Respondents felt that their doctors do not take them seriously enough, and some felt misunderstood, mistreated and discriminated against. One woman said,

It's quite different going to see my physician at the Brownlee's and going to my GP. I am not comfortable going to my GP ...having been here so long, I could sense some suspicion; it's not open, but I perceive a sense of discrimination. I have a problem with my blood pressure and he puts on gloves to check my blood pressure.

Another man pointed out that he would only go to a GP only if he was very seriously unwell. He said,

I see different GPs in the Practice and she asked me what was my condition. So I told her about fungal infections etc. and she asked me why did you not tell me you are HIV. And I said you have my records in front of you...I don't want to be reminded all the time about my status; HIV is not my second name.

Another woman's experience of going to the Accident and Emergency Department in a hospital in Glasgow echoed his sentiments about HIV not being their name. She said,

As soon as they check after taking your date of birth they want me to confirm what is my status: what is the point when they already have it on the system. We don't want to state our information everywhere. It's like everywhere you need to tell everywhere, everywhere HIV, HIV. It's like there are many diseases that are horrible than HIV, but they take HIV as a nasty disease. They don't care who you are or what is your name, they just see you as HIV. Why don't you give that as my name?



Several respondents felt they were discriminated against by dental practices and spoke with anger about their experiences. One man said,

I have stop going to the dentist because I feel pained by the way they treat me when I go there, particularly the dentist's secretary. They look at you with such disrespect...probably it's only my perception, but it happened each time, so I don't go at all.

Another woman spoke at length about her experiences of discrimination in her dental practice, but spoke very highly of her GP. She said,

I don't go to the dentist because I don't like the treatment. The nurses are very rude. The file has HIV written in bold letters on top, so you have no privacy. But my GP is very good and supportive; I can't complain about them.

Quite tellingly, seven other respondents criticized the dental care that they had received and said it was usually limited to either cleaning or removing teeth. One man jocularly said,

I have stopped going to the dentist because soon I will be left with no teeth, at all!

A few respondents spoke about feeling discriminated against, as soon as medical professionals became aware of their HIV-positive status. One woman spoke about her experience of NHS 24. She said,

The minute you tell them you have HIV they become so defensive. I had to wait for 12 hours and when the doctor came I was already better, but those hours when you could not breathe, when you were feeling so sick, what is the use.

Another woman said that she felt discriminated by the ambulance service and recollected a situation where she was unable to walk, but was not offered a hand, even when she asked for it.

The finding of our research in this area connects strongly with previous research conducted by Sinyemu and Baillie (2005) who noted, 'HIV becomes your name'.

V. Problems with the Cashless System

A few respondents who were in receipt of Section 4 payments spoke at length about the problems created by the new Azure card cashless system and how it prevented them from buying appropriate food to feed themselves and their children, or buying essential non-food items like telephone cards, household cleaning products or non-prescription drugs.

The respondents said that they were grateful for the money that they were being given, but pointed out that the system was extremely restrictive, as it did not allow them the freedom to buy what they wanted, where they wanted it from and when they wanted it. One woman explained,

The thing is that you are not able to buy African food, such as maize meal which is my staple food. You are forced to buy from like Tesco's and you have to spend 30 pounds. There are certain times when you feel so restricted, like you have no freedom to do even eat what your body needs and is used to, when you are not feeling well.

A few respondents spoke about the inhumanness of the cashless system, which prevented them from communicating with their loved ones who were either in different parts of the UK or in Africa. One woman, who was dispersed without her husband to Glasgow, became rather emotional. She said,

My children want to at least hear their father's voice and talk to him. I am willing to stay hungry to be able to buy some talk time, but the card will not let me to do that. How inhumane can they be?

Her sentiments were echoed by a woman whose children are still in Africa. She said,



I crave to hear my little ones voices; I crave to tell them mummy will send for you soon, I crave for just those few seconds. Is it too much for this Government to allow us this little human pleasure? Can't they understand, don't they have children too?

Reynolds (2010) highlights how the cashless systems of support within the UK heighten feelings of low self-worth, shame and pain.

VI. Pain, Shame and Stigma

The three words pain, shame and stigma were present in the narratives of majority of the respondents in both the individual and focus group discussions. The narrative of one of the respondents encouraged us to think of the three aspects together. As he put it simply,

HIV positive plus asylum seeker means you have pain, shame and stigma. Stigma because you are made to feel dirty and shameful by others, stigma because you make yourself to feel shameful and dirty.

The narratives of the respondents point to losses and stigma as the main cause of pain. Four respondents (all women) all spoke about the pain that the loss of a family member brought. One woman spoke about the pain of her son being killed by the ruling party in Zimbabwe, another about the pain of her father disappearing and her brother being murdered by a brutal regime in east-central Africa. Another spoke about the loss of her newborn baby in the UK and one other about her husband dying of AIDS in West Africa.

Another woman who had been gang-raped in front of her adult son spoke about the shame she experienced. Her narrative was poignant. She said,

Somehow, I can never forget the shame I felt and the terrible regret that my child, my male child had to see his mother go through that and he had to help me afterwards to get up and cleaned. It was terrible, too shameful. Even now when I think of it, I feel so ashamed.

Another woman who had also been gang-raped and very badly injured spoke about the shame and pain she experienced. She said,

I left my husband 9 years ago and my two young children because I was gang raped and needed treatment for my gun wounds. But now my husband has moved on, I feel so pained, I feel rejected by him, although I do not blame him, I feel terrible pain. I have lost my family and everything I knew. I can't go home because I do not belong there and I do not belong here.

Four respondents (all women) spoke about the shame they felt when they were told that they had HIV. They all said that they blamed themselves, even though they knew that they were in fact victims of terrible abhorrent crimes against them: gang rape, human trafficking and brutal domestic abuse. The narrative of one woman, who was gang raped voices the feelings of the other women. She said,

I was angry with myself and hated myself for becoming HIV. I felt ashamed that I had allowed myself to be used and thought of myself as bad person who has brought shame on herself and her family.

Sinyemu and Baillie (2005) found that most interviewees discussed feelings of devastation, loss and grief. They also reported feeling dirty, shamed and diseased. Most discussed their feelings in the context of knowledge and experiences of HIV in their own country, where diagnosis is believed to be a death sentence and is associated with a level of stigma. Almost all women interviewed blamed themselves.

Moreover some respondents spoke about the shame and pain they experienced when they were racially abused. Interestingly, all four men who were interviewed referred to pain in relation to racial abuse they had experienced. One man said that he was still pained a week after he had been abused. He said,

I was waiting in my pharmacy and one man came to me and sniffed, as if I was smelling



very badly, and said go home you bloody, bastard and stop living off our medicines.

Bernardes et al (2010) suggest that as well as shame and pain associated with HIV status, many asylum seekers also experience on account of the racial discrimination experienced by them.

A recurrent theme through all interviews was the pervasive stigma experienced by individuals in relation to being HIV positive and an asylum seeker. The majority of the respondents were only obliged to disclose their status to doctors, dentists and immigration officers at the UKBA, and these were the sources of stigma they described. One asylum seekers' narrative of her experience of stigma from her GP and her case worker at the UKBA encapsulates the stigma experienced by positive asylum seekers. Her narrative inspired the title of this report, You are AIDS. She said,

I remember that that time I was feeling dizziness... so I went to her and I said that I'm feeling dizzy. And she said Oh so you are XX (used her name) oh so you are your baby are AIDS. I felt offended, but I didn't answer, but I said, I am AIDS? And she did not answer she wrote something on the paper and on top of the paper she put a red paper and put HIV positive...I am not AIDS, I am HIV, my baby is ok, she is not HIV. So also when I went to the Home Office and my case worker asked me about my healthy status and so I did not say anything, because it was on the paper and so she said, "Oh you are AIDS" and I said I am not AIDS I am HIV. I was so offended, I said look at this one, you're from Africa you are AIDS, so like that ... they call me 'you are AIDS'.

Additionally respondents spoke about the stigma they imposed on themselves because they were HIV-positive. One woman said that she felt like a second class citizen in her own home, because she was the only person. She felt she was dirty and became obsessive about cleanliness and wanting to over-protect her family. She said,

The pain you feel because you stigmatise yourself is only something that can happen because of HIV.

This feeling was echoed by another respondent, who was persecuted by his country because he wrote against the tyrannical regime of his government. He said,

I have not experienced any stigma on account of HIV because I have not disclosed my status to anyone. The only exclusion that I have experienced is the one that I impose on myself. Having HIV makes me self exclude...I don't know how much I can really trust my fellow Africans.

The All Party and Parliamentary Group on AIDS (2003) draw attention to negative media attention towards immigration and HIV and argue that it perpetuates stigma and discrimination, which encourages inefficient and inappropriate policies. Crusaid (2007:14) found that all their service users reported HIV related discrimination and public perceptions of HIV as the biggest handicap to living well.

VII. Emptiness and Interminableness

Some respondents spoke about feeling a sense of emptiness in the present, being in limbo, having a sense of being stuck and not knowing when things would change. A significant majority said that being an HIV positive asylum seeker meant not knowing what is going to happen in the future and worrying about it in the present.

Some respondents were waiting to hear more about their claims; others were waiting to hear more about their appeals; yet others were wondering how long it would be before they were detained and deported. One woman explained that waiting for something to happen was the worst part of being an AS. Being HIV positive only complicated the uncertainty they felt about their future. As one asylum seeker evocatively put it, "One question always burns in our head: what will my tomorrow bring me my Lord?" And another tellingly added "Our life means waiting, waiting, watching and wondering, worrying".



One woman had the focus group participants laughing when she explained her strategy of living positively in the present and not worrying about the future. She said,

I am going to try and stay positive for as long as I can. Long time back when I was at home there was a lady who came out on television; she was being interviewed about how it was to live with a disease. She said I said to the disease you can only live if I am alive so you better behave so you can live longer in my body...

VIII. Multiple Jeopardy

Dealing with the difficulties of having a HIV diagnosis, at the same time as trying to cope with various issues involved with the asylum process clearly places HIV-positive AS in a position of double jeopardy. Being HIV positive and being an asylum seeker were seen by the participants as having to cope with two major difficult life circumstances at the same time. As one woman put it, “double trouble, double trouble”.

One woman said that had she only been HIV positive, she would have managed to deal with it more resolutely, but being an AS meant that she could be returned home and if that were to happen it would mean death on both counts. She said,

The most painful thing is the thought that you might be sent back to your country, where you will definitely die because they will find you and they will make sure you die and even if you are saved from them HIV will kill you.

Another woman noted that one problem made the other worse, and this created a vicious cycle, which made life much more difficult.

I got a letter from the Home Office that I can be sent home at any time and I cried for two days and could not eat at all... That made me so sick, so sick and I could not keep my appointments with the Home Office and so decisions had to be delayed.

Another woman said that her position was not one of 'double jeopardy' but one of 'multiple jeopardy'. She said,

I have so many problems, I ask myself so many questions ... It is just because I am black? Is it just because I am a woman? Is it just because I am HIV? Is it just because I am an asylum seeker?

During the focus group one man very powerfully and decisively narrated his views on the complex nature of the double jeopardy experienced by HIV positive asylum seekers. He said,

At least with HIV you know that the worse that can happen is that you will die, but this asylum thing, you don't know where you are going, where you will be taken to and what will the outcome be. The sad thing is HIV cannot be changed, asylum can be given and then we do not have to live in this double jeopardy.

IX. Solace from Social Support Networks

The accounts of majority of respondents reflected how a little social support goes a long way, when it comes to fostering strength and resilience. One source of such support was formal organisations dedicated to caring for this population. The Waverley Care African Health project and the THT (Glasgow) were cited by respondents. One woman who used both services said,

They make it personal. They make you feel you are the only person around, more than a friend. They really make you feel like an individual, like you really matter.

One woman spoke about her experience of doing voluntary work in an HIV organisation in Glasgow. Opportunities to volunteer gave this individual a sense of belonging and helped her to overcome depression. She said,

I have found this organisation to be very kind and supportive, they know I am



positive but they accept me as I am. I feel less lonely and sad.

Research evidences positive experiences of HIV-positive migrants being employed by voluntary services who support people affected by HIV (Fortier, 2003).

Church and church-related persons such as pastors and congregational members were also seen as a major support. One woman said,

I have gone through a lot, but the support and help from my own church has helped me and given me hope to go on and struggle and still go on.

Friends mainly fellow Africans (either from their own country or other African countries), were the other source of support.

One man even suggested that the Scottish Government had been a source of support for him. He said,

In general I have felt that this government, the Scottish Government, in its own way, in its limited capacity will do what it can to help with whatever little resources are available. They have been here to help me.

4.2.4 Hopes for the Future

When we asked people about their hopes for the future, they spoke about their aspirations for freedom, medical care, being united with their families, and having the right to live and work freely and be productive members of society. They also said that one of their hopes for their future was that their voices would be heard from this study.

I. Freedom

Four respondents whose asylum claims were successful in the past few months spoke about not being able to enjoy their freedom to be. One man described it as “freedom to be, to just be” because his HIV-positive status was not acknowledged

as one that required any special consideration or priority. He spoke about the scarce importance given to the fact that he had HIV and that as an HIV-positive man he had expected to be given some priority in terms of housing. He said,

I was so surprised to hear from a Housing Officer that HIV was even considered a medical condition that would get any priority... So you may have your freedom, but if you do not have a proper roof over your head, you do not have the freedom to be, to just be...

Another woman described her housing situation: lack of heating, bare floor boards, mould and mildewed accommodations, no cookers, no central heating etc., which all meant that she would be more prone to infections and more likely to become unwell and stay unwell. She said,

The sweetness of the freedom is taken away...especially in a season like this...no heating, no carpets, no cooker...I applied twice for a grant and was refused. So I am still having to live on ready made food, which are only making me feel sick, so it's really difficult.

Another woman lamented that she had the freedom to work and had a 16 hours per week job, which left her in poverty. She said,

You have the freedom to work, so I got a job for 16 hours, but now I must pay my rent, my council tax and everything else, so I have no money for heating and food...I love my freedom, but how can I live, how can I breathe like a really free person when I am getting strangled by my new poverty?

II. Medical Care

It was a hope repeated by many respondents: that all HIV-positive people are able to receive appropriate medical care and treatment irrespective of their immigration status, nationality or gender. One woman's narrative details her personal hope, but the hope itself was one shared by many of the respondents. She said,



I hope that all people with HIV will get the best treatment whether they are black or white, woman or man, African or Scottish or Indian or anything; whatever their status is at the time. That no one will be forced to go back to their country where they cannot be sure that they will get the right medication.

One man reiterated that they he was happy with the care received in Scotland, but believed that educating nurses, receptionists and dentists was of absolute importance, to make people feel secure and not discriminated against. He suggested that getting HIV-positive people to be part of the training would ensure that people understood the impact of their actions on real-life, authentic people living with HIV. He said,

HIV education will be the best thing for making the doctors, nurses, dentists, receptionists to understand. Education is the only way to make people understand what it is that is going on in our minds and how to talk and what to say.

One woman pointed out that it was important that everyone in a GP's practice and dentist's clinic is taught how to treat HIV positive people. In particular she stressed the importance of confidentiality. She said,

They should to understand that they do not call out our sickness before our names. They should be taught to treat us like other people, they should be taught to be most confidential with people's sicknesses. You don't hear them calling out loudly 'you diabetes go in now', 'you fever go in now' do you? Then why only HIV?

One respondent spoke about his hope for a law centre for positive people where HIV-positive people would have access to all kinds of legal information, as well as information on human rights, asylum, etc. He said that doing it all under one roof would help positive people to access legal services more easily.

III. Being United with One's Family

Four women spoke about their deep desire to be reunited with their families. One of the two women who were dispersed to Glasgow with their young children

said that her dream for the future was to have a 'settled, free, happy family life in Britain' along with her husband and child. The other woman's narrative was more reflective and subdued. She said,

I pray that we will be united one day soon and that the children will have their father back. My little one hardly knows her father. My sons are growing up without their father and I am struggling without him...what can I say? Sometimes I wonder whether this dream will come true for us here.

One woman, who was just granted asylum before we interviewed her, said that she could barely wait to be reunited to her children from Africa. However, she told us that the funding for Red Cross and the Scottish Refugee Council for family reunification had been cut and this meant that she might have to wait for years before she is able to fund her children. She broke down when she spoke,

Every time it is a quarter step and you stop and a quarter step and you stop. The Lord knows when I will finally get reunited with my beloved children. I just ache to be together with them and they want to be with me.

IV. The Right to Work and be Productive Members of Society

The majority of respondents stressed their desire for independence, self-respect and self-reliance. They believed that the only way they could gain these was through paid employment. One woman's assertion, below, reflects the feeling of the majority of respondents.

If you allow us to work we can be like you, we can be putting our heads up and working alongside with you.

Respondents were understandably emotional when one of the focus group members suggested a future free from stigma. Many felt that it could never happen, but all of them felt that it was something that they desired for their future.



One woman's narrative so poignantly seemed to represent the hope of the rest of the group. She said,

We want a life where people are human to all humans whether they are black, whether they have HIV or whether they come from Africa or whether they have a permanent leave to remain.

V. Having Their Voices Heard

At the end of the first focus group, one of the women said that it was her wish that the voices of positive asylum seekers should be heard. The researchers made a commitment that they would aim to disseminate their voices and to share their stories. The narratives reported in this document aim to do just this.

An older woman said that she wanted the Government to hear the voices of older HIV-positive asylum seekers and plan for their health care as they get older and require nursing care.

If we talk, the Government may listen... Somewhere, sometime we have to talk and we have to be heard, otherwise it is going to be a big problem. We are getting older, and somewhere something needs to be done about it, otherwise how will the care homes manage with us? How will we be able to ensure that at the end of our lives we are not being stigmatised again for being HIV positive? It will be even more unbearable when you are old and cannot have the mental strength to bear with things...

A woman from east central Africa implored with the researchers to tell the Home Office that all she wanted was peace and a chance to live.

I want to give a message to Home Office to leave people who have HIV positive, to give them peace. Please, please listen to us. There is no medications, they have no drugs, please we have had enough, we have enough and we are tired.

Another woman echoed her. She said,

Please let the Home Office hear our voices. Please tell them to hear our silent cries. No one wants to be HIV-positive, we don't make an application to get this virus, we don't take a vow to get this sickness. We are not criminals; we just need a house to be warm, we need the medication to be alive. Let us work and get the money to buy the tablets and take the medication, please give us our freedom to live in peace.

A woman from Zimbabwe became very emotional as she spoke. When she stopped talking she was in tears and so were many of the other respondents in the group.

We have come to a country who criticises Zimbabwe for not having human rights, for not taking human rights in to consideration. Where are the human rights where we have come to seek asylum, where we have come to look for hope that we might lead a better life? Where is it when we are watching our own fellow friends being denied asylum, being refused anywhere to stay, even if we have been given a house we cannot even house them because the law that states you cannot accommodate another? Where are the human rights in that? Can you tell us where are the human rights? You are supposed to be secure, because we can't feel it. You are supposed to be kind to people like us in our condition. We came here in the hope, in the hope for a better life. When we are HIV positive, for a much longer life ...where is it? For a much better life, where is it? Where is it when we are stressed, even when we are on medication, where is it? Oh please give us some hope, show us that you have got human rights, show us that much. Don't be hypocrites like the people we have run away from.

Finally, one man said that he wanted to give 'some food for thought to Britain'. He suggested that the best thing that Britain could do was to give asylum to people who are genuinely unwell. He said,

Help us when we are in hardships. Don't keep the sword dangling over our head. We already have two death sentences; take away one death sentence. Help us to live. We cannot give Britain rules on how to admit us in their country, but it's food for thought.



4.3 Conclusion

The quotations presented in this chapter paint a vivid picture of the hardships endured by HIV-positive asylum seekers as they try to cope with many adversities. In the next chapter, the findings will be discussed and recommendations will be offered.



4.4 Summary of findings

Coming to the UK	Seeking asylum in the UK	Being a HIV Positive Asylum Seeker	Hopes for the future
<p>Reasons for leaving one's native country</p> <ul style="list-style-type: none">• Fleeing a tyrannical political regime and politically motivated atrocities• Fleeing personal/familial gender-based violence and abuse <p>Victim of human trafficking</p> <p>Seeking treatment</p> <p>Becoming 'Overstayers'</p>	<p>Bewilderment and Uncertainty</p> <p>Issues in Relation to the UKBA</p> <ul style="list-style-type: none">• A place to fear• HIV minimised• Lack of understanding of issues in the native country of the AS <p>Dispersal and Detention</p>	<p>Fear of Disclosure</p> <p>Being under UKBA Surveillance</p> <p>Being a Failed Asylum Seeker</p> <p>Access to Medical Care</p> <p>Problems with the Cashless System</p> <p>Pain, Shame and Stigma</p> <p>Emptiness and Interminableness</p> <p>Multiple Jeopardy</p> <p>Solace from Social Support Networks</p>	<p>Freedom</p> <p>Medical Care</p> <p>Being United with One's Family</p> <p>The Right to Work and Be Productive Members of Society</p> <p>Having Their Voices Heard</p>



Key Issues

From vulnerability to vulnerability
Human Rights Issues
Multiple Jeopardy



Chapter 5: Discussion and Recommendations

We will discuss the findings in terms of three issues: moving from vulnerability to vulnerability; human rights issues; and the experience of multiple jeopardy.

5.1 From Vulnerability to Vulnerability

The narratives of respondents clearly highlight the issue of vulnerability in all their lives: both past and present. In a sense, it would appear that they have moved from one set of vulnerabilities to another.

A range of pre-migration factors such as conflict, war, poverty, trauma and powerlessness make AS more vulnerable to various illnesses, including HIV/AIDS (Davies, 2006; Spiegel & Nankoe, 2004; UNAIDS, 2010). The narratives of the HIV-positive AS in our research provide a chilling glimpse of the lives that these individuals left behind—persecution, violence, gang-rape, and discrimination as they fled their country, seeking to find a place of safety. However, a combination of post-migration factors (such as discriminatory and authoritarian policies, negative media coverage, stigma and discrimination, breakdown of families due to dispersal policies of the state, false perceptions and inadequate representation) continues to impact the ways in which asylum seekers' lives are shaped. Thus, these vulnerable individuals continue to experience further vulnerability and marginalisation within the host countries (Crawley et al, 2011; Fortier, 2003; Malloch & Stanley, 2005).

Many HIV-positive AS were forced to make difficult choices about staying in the UK to access treatment or return to their country of origin, where an early death is more likely. This result is in keeping with the findings of Sinyemu and Baillie (2005). Many participants in the current study also reported the government's argument regarding the availability of and accessibility of HIV prevention, care and treatment in their country of origin, notwithstanding the other critical factors that would increase their vulnerability if they are deported. For example all HIV-positive AS in this study had faced significant housing and

financial difficulties, stigma, and discrimination, with some assuming the role of a fugitive because they had no place to stay. This increases their vulnerability and ability to cope with the illness, and denies them their fundamental human rights. The narratives of HIV-positive asylum seekers in this study clearly portrayed a life that is “profoundly degrading and dehumanising” (Sinyemu & Baillie, 2005:33).

5.2 Human Rights Issues

The narratives of HIV-positive AS in this study bear out the deep and complex relationship between HIV and human rights. Despite the advances in care and treatment of people living with the illness, HIV continues to be a major social and public health concern across the world, shining a glaring light on the human rights of those affected by the virus, especially in relation to access to health care. Marginalised and vulnerable people such as women, children, and in particular AS, continue to face discrimination. Vulnerability to HIV infection feeds on violations of human rights, including discrimination against women, as well as and conditions that create and sustain poverty. Given the importance of human rights in HIV prevention and treatment, the international human rights system has explicitly recognized HIV status as a prohibited reason for discrimination. Either through legislation or litigation, many countries have recognized that their people have the right to HIV treatment as a part of their human rights, confirming that economic, social and cultural rights are justiciable (UNAIDS, 2006).

The International Guidelines on HIV/AIDS and Human Rights (UNAIDS, 2006) direct as follows:

States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasize education and conciliation, and provide for speedy and effective administrative and civil remedies (Guideline 5).



Guideline 8 also calls on States to 'promote a supportive and enabling environment' for women, children and other vulnerable groups. States are asked to deal with prejudice and inequality through community dialogue and to create specially designed social and health services and support to these vulnerable community groups. The accounts of all the respondents in our study bear evidence of discrimination and lack of protection they have encountered as they make their lives in the UK.

The UK Human Rights Act (1998) guarantees to protect the rights enshrined in the European Convention of Human Rights. However the accounts of the AS illustrate several instances where the following rights have been breached:

Article 3 outlines the right not to be tortured or inhumanly or degradingly treated or punished. Some respondents described experiences of being treated inhumanly by UKBA officials when they attend the UKBA office for their weekly/fortnightly reporting. Asylum seekers are being detained and removed to the detention centre without prior warning, and many reported that they have had to go with the officials to the detention centre without having collected their medication from their place of stay. This circumstance had a significant impact on their ability to comply with medication. Similarly, those AS whose claims and appeals have been rejected usually had their state support (Section 4 payments) discontinued four weeks after the decision. Once the state support was cut, these AS were left with no money to buy food, and many faced destitution. Without proper food and accommodation, these HIV-positive AS found it very hard to follow the HIV treatment. The stories of the AS in this study presented many instances of discrimination and denial of human rights. Several participants also reported experiences of prejudice and discrimination by dental practitioners and GP practices.

Article 8 articulates the right to respect for one's private and family life, correspondence and home, and Article 12 asserts the right to marry and found a family. Aspinall and Watters (2010:32) have drawn attention to the way that the circumstances of dispersal and treatment of failed asylum-seekers interfere with rights related to family life. Many AS in our study reported that their families were separated as a result of the dispersal policies of the UK government. This resulted in some of the family members being left in one

part of the UK while the others were brought to Glasgow, with no opportunity for a reunion. This left many of the participants isolated and depressed, as they found themselves in a strange place, once again away from their family and friends. Respect for human rights is essential for effective responses to HIV/AIDS, as infringements of human rights lie at the heart of marginalisation and the creation and continuation of vulnerability (UNAIDS, 2001). Furthermore, dispersal is seldom planned in advance and no consideration is given to the health/medical needs of an HIV-positive AS. As a result, many participants reported being brought to Glasgow, with no planned transfer of their medical records from one place of treatment to the other.

5.3 Multiple Jeopardy

HIV thrives in conditions of powerlessness, poverty, exploitation and social exclusion (Haour-Knipe, 2003). The accounts of the majority of participants in our study resonated with the above finding, leading them to forced migration and increased risk of marginalisation, discrimination and human rights abuses. The uncertainty of their immigration status only added to the multiple jeopardy they experienced.

The current study has highlighted the many difficulties in living with HIV while trying to cope with a variety of problems associated with the immigration system, placing HIV-positive AS in a position of 'double jeopardy', a finding which echoes the findings by Sinyemu and Baillie (2005).

One of the most palpable issues that emerged from the interviews in this study was the post-traumatic stress experienced by almost all the respondents. The interviewer found that respondents initially spoke in a very matter-of-fact/limited way and reported difficulty remembering some experiences. It almost appeared as though they were unwilling to fully engage. This reaction is similar to reactions reported in the accounts of torture victims. Talking about their memories to the researcher seemed to be the first stage of triggering traumatic re-experiencing. It is an understandable coping mechanism. Why would you want to go there? The very nature of traumatising makes it difficult



to recall, but also to verbally access the issues of the traumatising. When the respondents talked dispassionately, they did not have to access this pain; it was hard for them to express themselves in a verbally accessible way. The pain appeared to be held at an emotional level. Other indicators of post-traumatic stress were also reported. One of the respondents described having nightmares and another flashbacks before fortnightly visits with the UKBA.

Living with PTSD had a significant impact on the ability of AS to tell their stories convincingly, especially when interviewed by people in authority. It is telling that the researcher initially questioned the veracity of their narratives, because of the form that their presentations took. Given this reaction by a sensitive and motivated researcher who has their interest at heart, one might imagine the impact their narratives have on officials. What chance do traumatized AS really stand with officials who begin with a premise of wanting to screen them out, instead of screening them in? In a way this is the double jeopardy that they suffer: to get credibility as an AS you have to give a detailed account; however, their ability to tell a credible story was limited by their post-traumatic stress disorder, which had a vicious effect on their asylum claim.

Chantler (2011) argues that international human rights policy instruments and national policy processes for determining refugee status present particular challenges for female AS who have experienced sexual assault. Legal processes for those seeking asylum require individuals to share their story but ignores the power structures and interplay between race, gender, culture and ethnicity. In determining the credibility of AS applications, most officials rely on the applicants being able to share their story (due to a lack of concrete evidence), yet psychological and cultural barriers can impact on perceived credibility of stories (Melloy, 2007). For example, research indicates many women have difficulty with detailed disclosure and are more likely to experience shame/PTSD and attempt to protect themselves through disassociation (Baillot et al, 2009, Chantler, 2011 and Melloy, 2007). It is common for someone suffering from PTSD to appear “withdrawn, uninterested and detached” and to block/forget painful experiences (Melloy, 2007: 653).

The intimidating and hostile environment and the experience of being in a new country can also limit the applicants’ capacity to recount events of their

journey (Melloy, 2007). For instance, Chantler (2011) notes that women may associate male authority figures with their abusers and therefore be more fearful and less able to disclose information. As a result, judgments are often based on perceived inconsistencies in information, late disclosures and applicant demeanour (Baillot et al, 2009; Melloy, 2007). Moreover, decisions require subjective interpretation by interviewers who are not adequately trained or equipped to deal appropriately with people suffering from mental health issues (Chantler, 2011).

Thus, gathering evidence of the journey of AS pre-migration is particularly problematic, as is expecting people to describe traumatic experiences in one interview (Chantler, 2011). As Baillot et al (2009:208) have pointed out, “You cannot expect someone who’s been here a month to go into a hostile interview environment and disclose everything, it’s crazy”. Encouraging people to discuss traumatic experiences too early or at a point in their life when they are not prepared to deal with them can be psychologically damaging (Rosenthal, 2003). Application decisions continue to be made without taking account of the impact of PTSD and the influence of post-migration factors (Chantler, 2011; Melloy, 2007). Thus, one of the main issues for AS is that legal processes often establish truths that do not take into consideration “the whole story” (Melloy, 2007:675).

Uncertainty about the asylum claims preclude the AS from being allowed to work and often result in their being dispersed away from what little networks of support are available to them. This, combined with managing the health needs of an HIV-positive diagnosis, makes life particularly difficult. Fortier (2003) has also noted that HIV-positive AS often cannot buy certain foods they are used to eating due to restrictions placed on them by food vouchers or lack of income, a circumstance that was reported by our participants as well. AS therefore have to endure multiple forms of discrimination. Moreover, those AS whose claims have been rejected will also have the double trouble of losing their state benefits (section 4 payment), thus leaving them more vulnerable to destitution and non-compliance with medication. For HIV-positive AS who are granted permission to stay in the UK, difficulties still exist in being able to integrate and establish a good quality of life. Key challenges include managing



changing health needs, utilising transferable skills and disclosing HIV status (Fortier, 2003).

Living with an HIV-positive status is only one of a number of difficulties experienced by AS. The All-Party Parliamentary Group on AIDS (2003:16) describes immigrants and people living with HIV/AIDS as “two of the most stigmatised groups in today’s media and society”. They highlight the extent of negative media coverage, which links AS to public health concerns and terrorist attacks, and argue that punitive policies are driven by electorate desires in response to false public perceptions. The evidence presented here underlines the findings of the All-Party Parliamentary Group on AIDS, who point out the dangers of setting asylum and immigration policy in response to a media agenda. (The All-Party Parliamentary Group on AIDS, 2003:17).

It is not surprising that AS are more vulnerable to physical and mental health issues. The impact of their experiences of having a life-threatening illness and having to seek assistance as a vulnerable escapee from repressive conditions is a harsh reality. A major concern is the lack of cultural sensitivity to the difficulties that people fleeing persecution may face in being open about their HIV status at the outset of their asylum claim. As a result people’s accounts are routinely dismissed as not credible. Moreover, the management of HIV requires financial resources in order to maintain a proper diet and adhere to medication regimens. The lives of all the participants in this study were characterised by the stark absence of such resources.

Many authors emphasize the need to recognize the current stresses in the lives of refugees and AS, and to avoid focusing only on pre-flight experiences. Burnett and Thompson (2005) point out the many aspects of the life of an AS that may contribute to poor mental health outcomes. It is not difficult to imagine how the asylum process can exacerbate feelings of insecurity and helplessness, as those in the application stage have little control over the outcome of the asylum claim and their lives in the meantime. The dispersal scheme does not permit AS a choice in where to live, and the prohibition against working leaves them dependent on scant welfare provision. Moreover, those who suspect that they are infected with HIV but have not been tested may fear that a positive test could lead to deportation (Burnett 2002: 13; Gardner 2000). Understandably, while

dealing with such immense pressures, HIV-positive AS are unlikely to try to articulate their rights in order to overcome barriers to accessing healthcare. As outlined above, the most likely scenario is that they simply will not access care, and will ‘disappear’ until such time as they require emergency treatment.

5.4 Recommendations

This study has revealed a number of serious flaws in the current system for dealing with AS, particularly as they relate to AS who are HIV positive. Each issue is discussed below with a recommendation.

1. Asylum as a place of protection and safety. Clearly the participants in this study have come from extremely vulnerable circumstances—victims of abuse and domestic violence, human trafficking, and tyrannical regimes. Their circumstances have forced them to seek a safe place out of their country.

This circumstance calls for a rethink of how asylum seekers’ applications are processed. Applications should be processed promptly and with sensitivity, so that these individuals are not forced to move from vulnerability to vulnerability; but from vulnerability to protection.

2. No such thing as an ‘illegal’ or ‘bogus’ asylum seeker (Refugee Council, 2011). Under international law, anyone has the right to apply for asylum in any country that has signed the United Nations 1951 Convention Relating to the Status of Refugees and to remain there until the authorities have assessed their claim. It is therefore imperative that asylum applications are processed in the light of the above Convention, and not evaluated against a backdrop of political imperatives or media pressure. The immigration and asylum process should be redesigned so that it does not create fear and anxiety among vulnerable individuals.

3. Migration policies and asylum procedures and the right to work. Rejected asylum seekers in this study live from hand to mouth, in utter poverty, relying often on the kindness of others to survive, sometimes going hungry and sleeping rough. There is a need to revisit work-related rights and to give AS permission



to work if they have been waiting for more than six months for their cases to be concluded, or if they have been refused asylum but cannot be returned home through no fault of their own. This will prevent vulnerable people being left in a state of limbo for prolonged periods of time, will reduce the burden on the taxpayer, and will allow a small number of asylum seekers to support themselves and their families while contributing to the economy. Those who are allowed to stay in the UK will find it much easier to become part of British society if they have been given the chance to work (Amnesty International, 2011). People should be allowed to work and to access asylum support, legal representation and legal advice.

4. Stigma and discrimination in health care practices. Many AS reported a lack of appropriate awareness and sensitivity regarding HIV, which resulted in stigmatising and discriminatory attitudes and approaches from health care practitioners and their receptionists: GPs, Dentists, NHS 24, and Ambulance Services. There is a clear need for culturally sensitive awareness training, targeting specifically at influencing attitudes and approaches of health care providers and health service staff towards HIV-positive AS. Such a programme should also include developing more culturally competent services, tailor-made to the needs of HIV positive people.

5. Lack of understanding regarding availability of treatment for HIV. Many participants in the current study reported on government representatives' misunderstanding regarding the availability of and accessibility of HIV prevention, care and treatment in their country of origin. Such misunderstanding can often lead to deportation of people who have no treatment options in the country of origin. This increases their vulnerability and ability to cope with the illness, and denies them their fundamental human rights, as they are unable to access appropriate care and treatment.

There is a need for the UKBA to develop a clearer understanding of the availability and accessibility of appropriate care and treatment for HIV in the country of origin of the AS, before deporting AS. Deportation can not only deny AS the right to health; it can also worsen health conditions, potentially leading to the death of AS. While claimants' narratives need to be deemed credible and consistent, they need to be cross-checked more thoroughly with information about the country of origin.

6. Lack of commitment to human rights. The narratives of HIV-positive AS in this study bear out the deep and complex relationship between HIV and human rights. There were several instances where discriminatory practices impacted the human rights of these AS. There is a need to renew our commitment to human rights as a cornerstone for informing policy and practice in relation to HIV-positive AS. Government authorities should end human rights violations such as the policy of destitution that affects the health of individuals. The authorities should provide leave to remain, permit AS to work, and allow for access to food and other necessities of treatment.

7. Dispersal and family breakdown. Some AS in our study reported that their families were separated as a result of the dispersal policies of the UK government. This left many AS isolated and depressed, as they found themselves in a strange place, once again away from their family and friends.

Right to family life is enshrined in the Human Right Act, and respect for human rights is essential for effective responses to HIV/AIDS, as infringements of human rights lie at the heart of marginalisation and the creation and continuation of vulnerability (UNAIDS, 2001). Furthermore, dispersal is seldom planned in advance, and no consideration is given to the health/medical needs of an HIV-positive AS. There is a clear need to rethink ways in which dispersal can be improved, such that the negative effects of dispersal on HIV-positive AS can be eliminated.

8. Post-traumatic stress and its implications for the asylum claim. One of the most palpable issues that emerged from the interviews in this study was the post-traumatic stress experienced by almost all the respondents. Living with PTSD had a significant impact on the ability of AS to tell their stories convincingly, especially when interviewed by people in authority. Legal processes for those seeking asylum require individuals to tell their story but ignore the power structures and interplay among race, gender, culture and ethnicity.

There is therefore a clear need to engage counselling and psychological services from early on to deal with the trauma and stress experienced by HIV-positive AS. Assessment and treatment for PTSD should be carried out as a matter of course, and AS should be provided with advocacy services that will empower



them to tell their stories.

9. Collective voice from the medical consultants. Many respondents in the study reported on the support and care that HIV positive AS received from the consultants and other allied health professionals at the clinic they attended on an individual basis. This was, however, limited to their care and treatment. There was a strong message that consultants should campaign and advocate for these vulnerable individuals with their local politicians and raise the profile at the central government level by lodging complaints and supporting campaigns to help AS, such that their voices will inform policy decisions.

10. Funding for voluntary organisations. It was evident that the work done by the voluntary organisations in supporting the HIV positive AS was exemplary; however many of these activities relied on very tight, and ever shrinking budgets. The sustainability of these organisations is dependent on guaranteed funding, and there is a need for clear commitment from the government to continue this funding for enabling AS to integrate better into the wider community.

11. Advocacy services. A majority of the participants in the study reported life-threatening issues in their lives which forced to seek asylum in the UK. Several of them showed symptoms of PTSD which, coupled with dispersal, made them more isolated and depressed, as they found themselves in a strange place, once again away from their family and friends. It was evident that they lacked the knowledge and skills in dealing with the bureaucracy. It is therefore vital that special advocates are appointed for each applicant at the time of first application, so that each AS will have a person who can guide them through the entire process, who can also speak the native language, and who will have sufficient sensitivity to understand their needs and their limitations.

12. Pseudo-illegal status of failed AS. The main issue for failed AS is their pseudo-illegal status in UK: they need to either be required to return to their home countries if their asylum claims are indisputably groundless, or to achieve a permanent and sustainable legal status. The most appropriate solution for an AS without high support needs, then, would be to put them in touch with a legal service to ensure that there is no further legal recourse for them in terms of their asylum claim and, if there is no recourse, to initiate voluntary repatriation or deportation.

13. Refused asylum seekers and return to Zimbabwe. An ongoing legal action prevents the Government from removing refused asylum seekers to Zimbabwe. Steps should thus be taken to provide a safe haven for destitute Zimbabweans (Amnesty International, 2011).

5.5 Conclusion

This study has uncovered the plight of HIV-positive asylum seekers as they try to establish new lives for themselves in the UK. The many obstacles they face have been discussed in view of the human rights and medical care issues that these obstacles present for this vulnerable group. It is time for a new approach to dealing with these individuals, whose numbers are relatively few, but whose suffering is great. It is hoped that the current study will help to provide a voice for these individuals and that the appropriate authorities will recognize the need to change policies and procedures to recognize the fundamental human rights of a vulnerable and misunderstood group.

"I like using my head, I like using my brain, I feel I am just sitting like a cabbage. I am scared everyday, every single day. I dream of freedom, to be able to live freely without any fear. Britain can help us, let them show the world that they believe in the human rights that they speak about" (from a Zimbabwean woman respondent in the study)

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